Care pathways in Traumatic Brain Injury rehabilitation: searching for the missing pieces

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TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

LIST OF APPENDICES

"No head injury is too severe to despair of nor too trivial to ignore"

Hippocrates, circa 400 B.C. [1, p.241]

"The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition"

Constitution of the World Health Organisation [2]

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AUTHOR CONTRIBUTIONS

Scoping review: screening of abstracts and full texts conducted by Tommer Spence and Inès Kander.

DECLARATION

This thesis is submitted to the University of Warwick in partial fulfilment of the degree of Doctor of Philosophy. It has been composed by myself and has not been submitted in any previous application for any degree.

DISSEMINATION OF WORK PRESENTED IN THIS THESIS

POSTER PRESENTATIONS

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- Playford, ED. & **Kander, I.** 2019. Developing an evidence base around community pathways and patient experience following brain injury. *UK Acquired Brain Injury Forum (UKABIF) Annual Conference.*

ABSTRACT

BACKGROUND

An important proportion of people who sustain a mild Traumatic Brain Injury (TBI) experience persisting symptoms, and may therefore present a number of rehabilitation needs. The care journeys for this patient population are not well understood, and there are few clinical practice guidelines defining care pathways in rehabilitation settings. The aim of the work presented in this thesis was to explore the current state of rehabilitation for this patient population with a view to developing robust care pathways.

METHODS

This project used a combination of traditional and novel approaches to healthcare research and is divided into three parts:

1) an overview of the literature including a scoping review aiming to clarify the current understanding and approach to care for people with Post-Traumatic Brain Injury Syndrome (P-TBI-S), and a detailed analysis of case reports to highlight any points of convergence in the care journeys of a heterogeneous group of patients with P-TBI-S.
2) an exploration of patient education materials about persisting TBI symptoms and a mapping of current care pathways through the interview of clinical and support stakeholders in the local area.
3) a collaborative project with brain injury survivors to explore new avenues for patient self-management support and research on service use and support needs.

RESULTS

The review of the literature showed a lack of research on the wide scope of care pathways from acute to community settings, including a paucity of care guidelines for the rehabilitation of patient with persisting TBI symptoms. The analysis of case reports showed common features in both functional deficits and patterns of access to services between seemingly highly heterogeneous patients. Educational materials distributed to patients at discharge from A&E departments across England following mild TBI are comparable but downplay the risk of developing persisting symptoms. They are vague in their self-management advice and signposting towards further care and support services. Care routes are fragmented, especially in the transition from acute to community settings. The lack of an effective pathway leads to the emergence of care silos and heightens the risk for patients to fall through the gaps of care at numerous points along their journey. General practitioners are key in identifying atypical recovery patterns and redirecting patients

towards appropriate services, of which the availability and accessibility was unequal across the different catchment areas of care providers. Currently, the management of these patients largely consists of education and reassurance, and symptomatic treatment, partly due to limited and inconsistent referral routes. A concept mobile app to support self-management, (including promoting re-access to care services as needed, and enable large-scale service use research) was co-developed in collaboration with brain injury survivors.

CONCLUSIONS

There is little research on the care journeys of people with persisting symptoms following TBI, leading to a lack of practice guidelines. The lack of clinical practice guidelines is associated with a lack of defined rehabilitation pathways for people with persisting symptoms following mTBI, both at national and local levels. Access to further care depends on service availability and accessibility, and there are no clear referral routes. At present, care largely relies on education, reassurance and symptomatic management. However, the lack of oversight of patients' care journeys and defined pathways leads to the emergence of care silos, thus increasing the risk for patients to fall through the gaps of care. More research is needed to explore patients' care journeys, evaluate outcomes of care and develop robust rehabilitation care pathways for this patient group.

ABBREVIATIONS

A&E	Accident and Emergency
ABI	Acquired Brain Injury
CCG	Clinical Commissioning Group
CCM	Chronic Care Model
CERU	Central England Rehabilitation Unit
CNRT	Community Neurorehabilitation Team
CT	Computed Tomography
DAI	Diffuse Axonal Injury
DMN	Default Mode Network
DVLA	Driver and Vehicle Licensing Authority
EP	Expert Patient
GCS	Glasgow Coma Scale Score
GP	General Practitioner
IAPT	Improving Access to Psychological Therapies
ICF	International Classification of Functioning, Disability and Health
LoC	Loss of Consciousness
MRI	Magnetic Resonance Imaging
mTBI	mild Traumatic Brain Injury
MTC	Major Trauma Centre
MTN	Major Trauma Network
MTU	Major Trauma Unit
NHS	National Health Service
PAM	Patient Activation Measure
PCS	Post-Concussion Syndrome
PIL	Patient Information Leaflet
PPI	Patient and Public Involvement
PTA	Post-Traumatic Amnesia
P-TBI-S	Post-TBI Syndrome
RAD	Role-Activity Diagrams
R-CS	Rehabilitation Core Set
RTC	Road Traffic Collision
SMOG	Simplified Measure of Gobbledygook
SRC	Sports Related Concussion
TA	Thematic Analysis
TAU	Treatment as Usual
TBI	Traumatic Brain Injury
TBI-CS	TBI Core Set
UK	United Kingdom
WHO	World Health Organisation

CHAPTER 1 - TRAUMATIC BRAIN INJURY

Traumatic Brain Injury (TBI) is a major global public health problem associated with numerous healthcare challenges. TBI is complex and heterogeneous in nature, affects all age groups, and can lead to significant yet non-specific clusters of symptoms that render return to pre-injury status difficult.

In this chapter, TBI will be defined, its epidemiology will be explored. Pathophysiology of injury will be discussed in the context of outcomes of TBI and recovery trajectories.

DEFINITION

TBI is a type of Acquired Brain Injury characterised by rapid-onset damage to the brain (Figure 1.1). The World Health Organisation (WHO) defines TBI as "an acute brain injury resulting from a mechanical energy to the head from external physical forces" [3]. "TBI" has historically been used interchangeably with "head injury". However, the term "TBI", accompanied by a severity indicator, is now preferred, as a way to emphasise the importance of brain damage in these injuries [4].

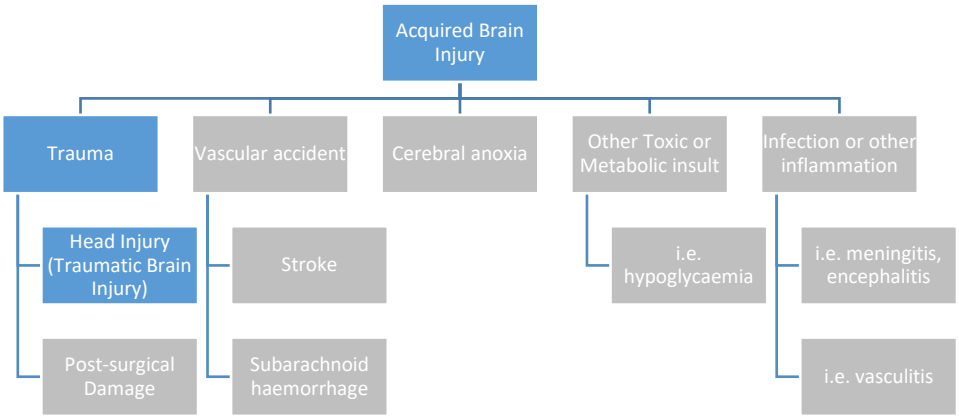


Figure 1.1. Traumatic Brain Injury within Acquired Brain Injuries

(adapted from Royal College of Physicians [5])

CATEGORICAL / HISTORICAL CLASSIFICATION

TBIs can be penetrating, perforating or blunt. In a penetrating injury, the outermost layer of the meninges is breached by an object. In a perforating injury, the object of the insult penetrates and exists the head. In a blunt injury, the object of the insult (when an object is present) does not breach the dura matter. The majority of TBIs are blunt, and will be the focus of this thesis.

While the definition of TBI in itself is seldom contentious, maybe because it is so broad, the lack of consensus lies in the categorisation of TBIs by severity. A 2014 report from the WHO

Task Force on mild TBI identified 38 definitions for the classification of TBIs [6]. The authors noted that in the wide variation were some overlapping criteria. The majority (62%) used the Glasgow Coma Scale score (GCS), 38% used Loss of Consciousness (LoC), Post-Traumatic Amnesia (PTA), the Abbreviated Injury Severity Score, or International Classification of Diseases codes. Most commonly, a combination of GCS, PTA and LoC is used to determine TBI severity [7-9] (Table 1.1).

Table 1.1. Classical severity classification for TBI[10]

	Mild Injury	Moderate Injury	Severe Injury
Glasgow Coma Scale score	13 – 15	9 – 12	4 – 6
Posttraumatic Amnesia	0 – 1 d	>1 – <7 d	≥7 d
Loss of Consciousness	<30 mn	30 mn – 24 h	>24 h

Developed in 1974, the GCS score is the most commonly used proxy measure of severity of brain trauma [11]. It enables a wide range of Health Care Professionals (HCPs) to quickly judge a patients' level of consciousness by assessing their eye opening, verbal and motor responses. However useful in triage for acute care provision, GCS score has been found to be poorly correlated with functional outcome [11]. In addition, the inter-rater reliability of the GCS is poor. Alternatives to the GCS, such as the FOUR score [12] and the simplified motor scale [13], have been proposed, but the use of the GCS remains predominant in clinical practice. Duration of PTA and LoC are generally better predictors of functional outcome than GCS [14,15]. Overall, the combined use of GCS, PTA and LoC measures provide a more balanced picture of injury severity which considers both immediate and longer term prognosis [16].

TERMINOLOGY DEBATE AND SPECTRUM APPROACH

Beyond debates around severity classification of TBIs, the field is also divided in regard to the place of "concussion" [8]. Some argue that concussion is distinct from mTBI in that it is a "functional rather than structural injury of the brain" [17]. Harmon et al. proposed that concussions are in fact mild TBIs as the functional disturbance stems from complex pathophysiological processes [18]. Indeed, "concussion" and "mTBI" are often used interchangeably in the literature [6 19]. Overall, it can be considered that concussion is in fact a clinical syndrome of mild TBI [20]. "Concussion" is prevalent in sports injury research, and is in this context defined as distinct from mild TBI [21]. The proposed definition of concussion as a "complex physiological process affecting the brain" in the sports literature allows room for inclusion of injuries presenting with neurological damage, although the sport literature approach heavily focuses on concussion as a set of functional impairments. Regardless, it has been suggested that the use of "concussion" to designate mild TBI is misleading to both

patients and clinicians. Sharp & Jenkins argue that the "concussion" label provides reassurance to the patient that the injury is benign, and to the clinician that, as it is not necessarily rooted in structural damage, "nothing can be done to help" [8,22-25]. This separation between concussion and TBI potentiates poor access to care, particularly in the acute post-injury period, as patients presenting to Accident & Emergency departments with concussions are typically sent home with advice for self-management alone [26]. Sharp & Jenkins suggest that the separation of "concussion" and TBI of different severity grades is outdated in light of scientific developments in the understanding of the pathophysiology and outcomes of TBI. They propose that the concept of "concussion" as separate to TBI should be dismissed, and that the classification of TBI should separate degree of structural damage and post-injury symptoms (Figure 1.2).

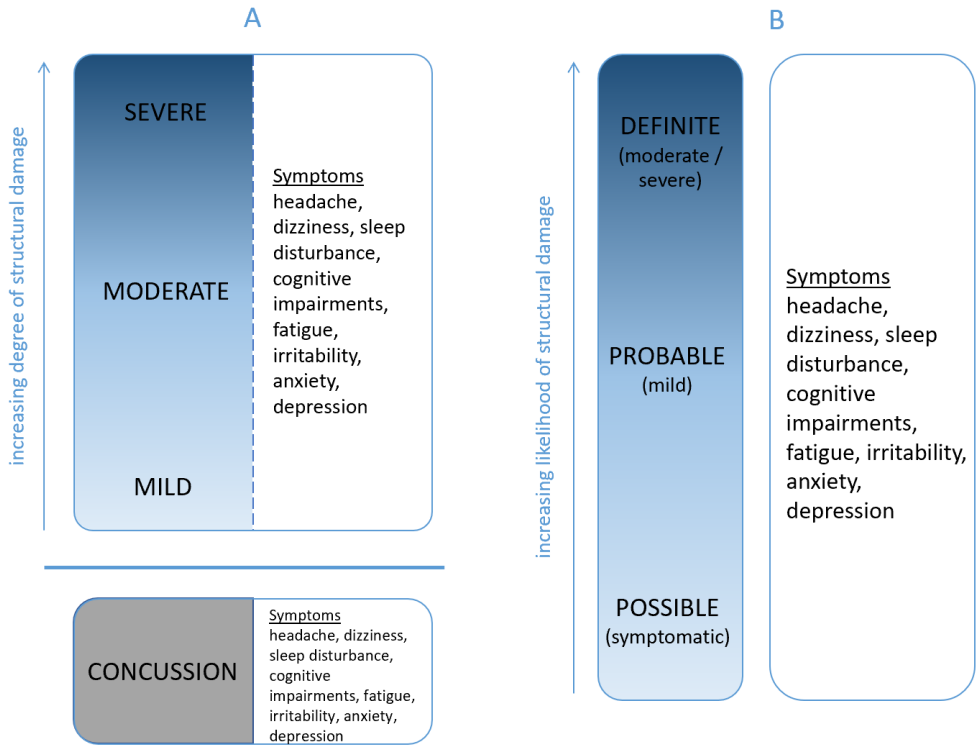


Figure 1.2. Historical TBI classification (A) and proposed classification separating structural damage and symptoms (B)

(adapted from Sharp & Jenkins, 2015 [8])

PATHOPHYSIOLOGY

Damage from TBI can be divided into focal and diffuse, with injuries typically spanning both categories. Focal injuries include contusions, and intraparenchymal haemorrhages. Diffuse damage includes axonal, hypoxic-ischaemic and microvascular injuries [7].

TBI can also be divided into primary and secondary injuries. Primary injuries include skull fractures and superficial head damage, haemorrhages, contusions, and white matter damage [8]. Secondary injuries include hypoxia, anoxia and necrosis, as a consequence of disruption in blood supply and swelling driven by inflammatory processes [7,27]. Damage from primary injuries is generally unalterable, however, secondary brain injury has the potential to be reversible. As such, the current care approach for patients with TBI aims at evaluating and subsequently minimizing risk of secondary brain injury associated with raised intra-cranial pressure [28,29].

Advances in understanding of TBI pathophysiology, particularly around diffuse injury, support a spectrum approach, and the abandonment of "concussion" as separate from TBI.

STRUCTURAL DAMAGE

Diffuse Axonal Injury (DAI) is a type of diffuse damage resulting from acceleration/deceleration forces occurring in TBI. It is characterized by axonal shearing and micro bleeding, and is considered to be the predominant pathological mechanism in mild TBI [30]. As opposed to localised contusions, DAI is widespread and can therefore impact neurological processes throughout the brain. A prime example of the consequence of DAI in TBI is its impact on sleep, a process that is heavily reliant on widely distributed brain networks [31]. DAI can occur during the initial trauma, but also appear and continue developing in the days, weeks, months or even years after the injury due the biochemical cascade that follows brain trauma [32].

Computed Tomography (CT) is a rapid and relatively inexpensive imaging technique used as the routine modality for TBI assessment. The main purpose of imaging in TBI assessment is to identify patients at risk of developing secondary injury, and who may require neurosurgical interventions [29,33,34]. As such, it is generally reserved for patients presenting with suspected moderate or severe injury [26]. In that respect, CT is an appropriate imaging technique to use, as it has a high sensitivity for bone damage and acute haemorrhage [9,35]. However, CT does not have high resolution, and may therefore not detect smaller bleeds, especially when close to the bone where they can be mistaken for artefacts [28].

In less severe cases of TBI, CT imaging findings are often inconclusive, and as such not routinely ordered for patients with mild TBI, at the same time minimizing radiation exposure

and resource use [28,36,37]. There are cases in which a CT scan will be ordered for patients presenting with mild TBI. Such cases are generally identified by using two sets of rules: the Canadian head CT rule and the New Orleans criteria [38] (Table 1.2). These take into account a variety of risk factors in addition to GCS, PTA and LoC, such as age, vomiting, and seizures.

Table 1.2. CT decision rules

CT=Computed Tomography; GCS = Glasgow Coma Scale score, LoC=Loss of Consciousness; PTA=Post-Traumatic Amnesia

Canadian head CT rule [39]	**New Orleans criteria [40]**

Inclusion:
- GCS 13-15
- Age ≥ 16y
- No coagulopathy / anti-coagulation medication
- No obvious open skull fracture
- Any of the following:
  ○ Age ≥ 65y
  ○ Vomiting >2 times
  ○ Suspected skull fracture (including signs of basal skull fracture)
  ○ GCS <15 at 2h post-injury
  ○ Retrograde amnesia >30m
  ○ Dangerous mechanism of injury
  ▪ Pedestrian struck by vehicle
  ▪ Ejection from motor vehicle
  ▪ Fall from height > 3’
	Inclusion:
	- GCS 15
	- Age ≥ 18
	- Blunt trauma in last 24h causing LoC, PTA, or disorientation
	- Any of the following:
	  ○ Age ≥ 60y
	  ○ Headache
	  ○ Vomiting
	  ○ Drug or alcohol intoxication
	  ○ Persistent anterograde amnesia
	  ○ Visible trauma above clavicles
	  ○ Seizure

More advanced Magnetic Resonance Imaging (MRI) techniques, such as Diffusion Tensor Imaging are much more compelling in revealing microscopic white matter lesions such as DAI [41-43]. Although not widely used acutely in routine medical care for patients with TBI, these imaging findings are helpful in understanding the existence and persistence of TBI sequelae in seemingly milder injuries [8].

PHYSIOLOGICAL CHANGES

Functional imaging methods can provide a more comprehensive picture of the pathophysiological mechanisms of brain injury [44]. These show that while focal damage may not be apparent, communication between different structures may be impacted, resulting

in functional deficits. In particular, it has been proposed that alterations in resting-state network activation may be at the root of at least some functional changes following TBI.

> Resting-State Networks
>
> In 2001, Raichle et al. [45] sought to explore the baseline activation state of the brain. They proposed that while functional imaging studies tend to focus on task-dependent activation increases, they largely fail in exploring decreases as they lack a definition of a true, zero activation, 'baseline' state. Raichle et al. showed that at rest (awake with eyes closed), the brain is in highly organised state of activation. This 'default' state of activation was coined the 'Default Mode Network' (DMN). In the following years, the DMN was shown to be part of several resting-state networks [46-48].

Neural connectivity studies show changes in TBI. Johnson et al. [49] showed changes in the DMN [45] following TBI, and an overall decrease of connectivity. Iraji et al. [50] found a slight increase in connectivity for patients with mTBI compared to healthy controls, and suggested that this may be the result of compensatory strategies in response to pathophysiological changes. Overall, studies of resting-state abnormalities in patients with mild cognitive impairments show patterns of alteration of the DMN to be complex and variable [51]. These studies show both that hyper- and hypo-connectivity can result from TBI, thus reinforcing the idea that functional deficits following TBI are at least partly rooted in pathophysiological changes.

OUTCOMES OF TBI

FACTORS INFLUENCING OUTCOME

Work on TBI outcomes also supports the spectrum approach to TBI severity classification, as it shows that TBI can result in long-term sequelae irrespective of initial injury severity category [9,52,53]. Indeed, it would be reductionist to assume that functional outcomes are solely dependent on structural damage. The WHO International Classification of Functioning, Disability and Health (ICF) [54] proposes a model of health which integrates multiple factors (Figure 1.3). This holistic approach to health in the ICF is a recent development. At its inception in the 1980s, the ICF, then called the International Classification of Impairments, Disability and Handicaps [55] adopted a disease-centric approach classifying "consequences of disease" [56]. Since then, it has moved towards a function-centric approach classifying "components of health", allowing for the description of both ill and good health.

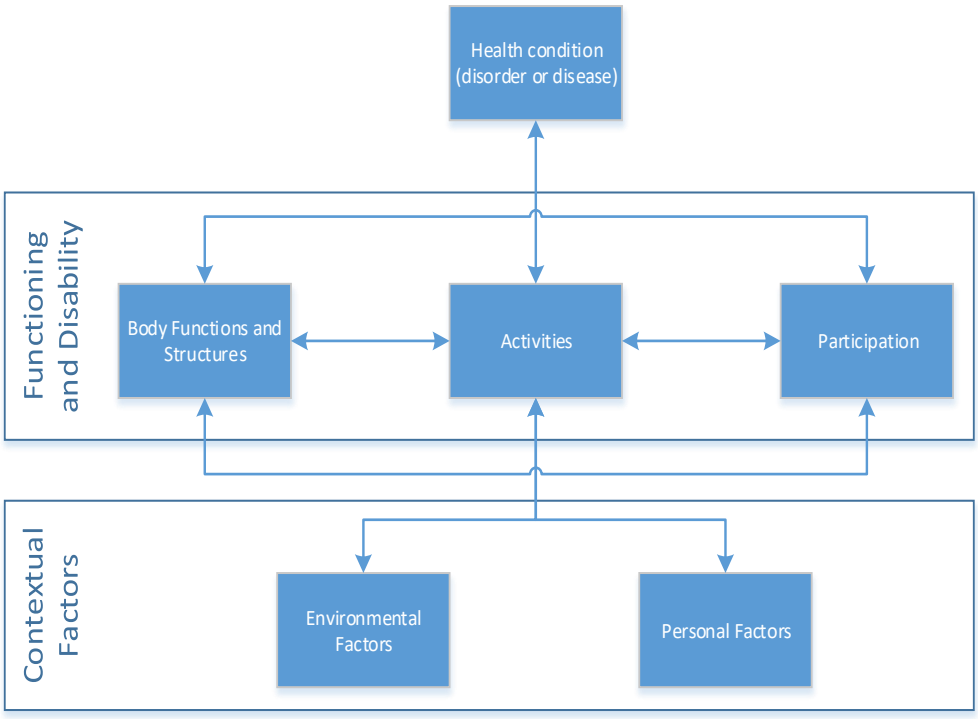


Figure 1.3. ICF Model

(adapted from WHO, 2001[54])

SHORT-TERM IMPACT OF TBI

Immediate symptoms following a TBI are well documented, and often include headaches, nausea, photophobia, phonophobia, mood changes, and cognitive difficulties. In the majority of cases of mild TBI, these symptoms fade away within a few weeks of injury, although there are debates around the length of the typical recovery timeframe (see Table 3.2 in Chapter 3).

Recovery time in TBI is variable [8,9,57]. The presence of co-morbid conditions such as Post-Traumatic Stress Disorder, particularly prevalent in military personnel with TBI, can complicate and delay TBI diagnosis and, subsequently, recovery [58]. Even in isolated mild TBI, the prognosis can substantially differ from one patient to the next. In mild TBI, post-injury symptoms generally dissipate within a few weeks, but in a significant minority (around 30%) it can persist for longer than 3 months [9] (Figure 1.4). In addition, the progression of symptoms is not necessarily linear, and their severity or impact on functioning can be exacerbated by numerous contextual factors [59].

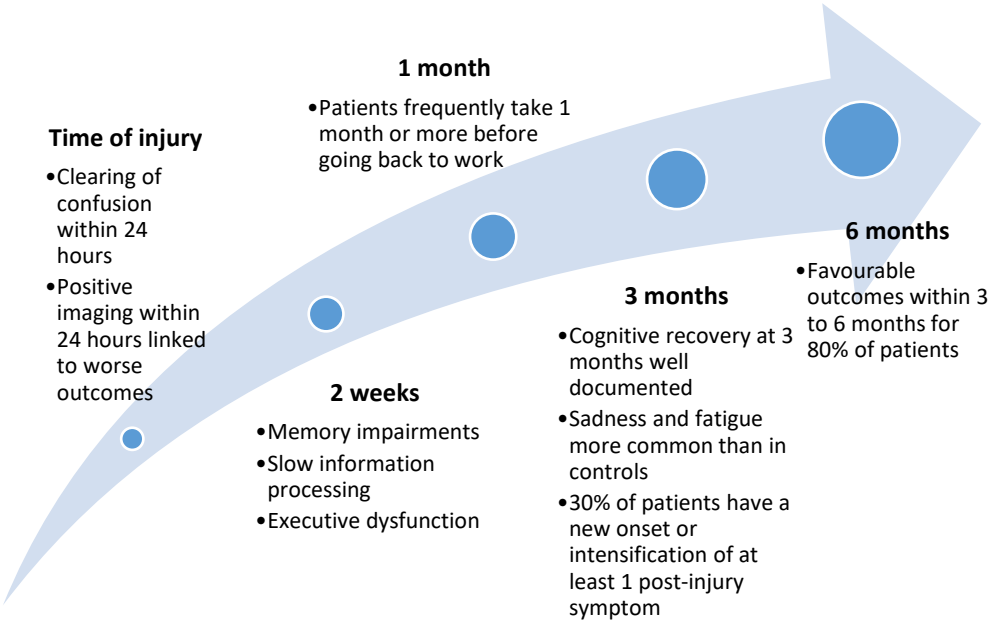


Figure 1.4. Prognosis timeline in mild Traumatic Brain Injury

(adapted from Levin & Diaz-Arrastia, 2015)

PERSISTING SYMPTOMS

TBI can have significant and lasting repercussions regardless of initial injury severity. The symptoms resulting from TBI are generally non-specific and variable in their intensity [60-62]. The terms "concussion" or "Post-Concussive Syndrome" (PCS) and "Persisting PCS" are often use to designate these symptoms [8]. This variable terminology is a consequence of the lack of consensus discussed previously. In line with the spectrum approach to TBI, these persisting symptoms will be referred to as part of a "post-TBI syndrome" (P-TBI-S) in this thesis.

P-TBI-S symptoms span a number of domains: somatic, cognitive, affective, and sleep [63,64]. Although this classification is helpful in getting a quick overview of domains affected by TBI, it does not for allow for the description of cross-loading (or the patterns in which deficits in the different domains occurs). This can be significant in early post-acute stages, when patients are most likely to be assessed for potential referral to specialist services. Collins et al. proposed that outcomes of TBI should be divided into 6 different "trajectories", or patterns of dysfunction, which allow for overlap between the traditional 4 categories [64] (Table 1.3).

Table 1.3. Patterns of Post-TBI Syndrome

(adapted from Collins et al., 2014 [64])

Traditional categories ↓	"Trajectories" → Symptoms ↓	Cognitive / Fatigue	Vestibular	Oculomotor	Anxiety / Mood	Post-traumatic Migraines	Cervical
Somatic	Fatigue	■		■	■		
	Decreased energy level	■					
	Non-specific headaches	■			■		■
	Frontal headaches			■			
	Migraine					■	
	Dizziness		■				
	Nausea		■			■	
	Balance problems		■				
	Pressure behind the eyes			■			
	Difficulty focusing vision			■			
	Photo/phono sensitivity					■	
	Neck pain						■
Cognitive	Difficulty concentrating	■					
	Memory problems	■		■		■	
	Slow processing speed	■	■				
	Fogginess		■		■		
	Feeling detached		■				
	High reaction time		■	■			
	Difficulty in busy/complex environments		■				
	Distractibility			■			
Affective	Anxiety		■		■		
	Hypervigilance				■		
	Sadness				■		
	Hopelessness				■		
	Emotional lability				■		
Sleep	Sleep disruption	■			■		
Key	■ Symptom present						

This approach is key to understanding the subtle variations in the specific impact of P-TBI-S on each individual, and therefore improve clinical decision-making for rehabilitation interventions. Collins et al. suggested that while performance on specific assessments may be similar between patients, the causes of suboptimal performance may be different. For example, poor performance on a memory assessment in a patient on the cognitive/fatigue

trajectory may be due to difficulties concentrating, but due to visual impairment in a patient on the oculomotor trajectory. Although both patients would show comparable decreased results on memory assessments, they may require different rehabilitation interventions.

PREDICTING OUTCOMES

The nature of TBI is complex, and its outcomes are driven by multiple factors. Outcome prediction is a core part of TBI rehabilitation research. Outcome prediction research examines pathophysiological, genetic, epigenetic, neurophysiological pre-injury [65] and early functional markers [65-68] to identify patients at risk of poor outcomes following TBI. More recently, studies have focused on the integration of these factors to propose more comprehensive predictive models [69,70].

EPIDEMIOLOGY

TBI is a major public health problem worldwide, and the leading cause of disability and death in young people in high-income countries [4,71]. Although reports of incidence vary greatly, even conservative estimates advance that between 100 and 300 per 100,000 people sustain a TBI in the world each year [72-74]. Epidemiological data on TBI is scarce, as people with mild TBI, which represents 80 to 90% of all TBIs [75,76], do not always seek medical attention [19,77]. Mild TBI alone is thought to be more prevalent than cancer, Acquired Immunodeficiency Syndrome, multiple sclerosis and spinal cord injury combined [19]. In the UK, each year, over 1.4 million people attend A&E departments for TBI [4,78]. In spite of these numbers, the scale of the TBI problem is thought to be vastly underestimated, both quantitatively and qualitatively [9,79,80].

Incidence of TBI is difficult to establish, due to methodological shortcomings in population-based research. TBI and the populations it affects are highly heterogeneous, resulting in significant study design challenges [3,6]. The causes of TBI are numerous, and variable between world regions and age groups. Road Traffic Collisions (RTCs), falls, sports injuries and assault are amongst the most common causes of TBI [77,81]. RTCs are a major cause of TBI worldwide, mainly affecting vehicle occupants in high-income countries, and more often cyclists, motorcyclists and pedestrians in low income countries. RTCs primarily affect adults of working age [4]. In Europe and in the United States, falls are also a major cause of TBI, disproportionately affecting young children and the elderly [73,81,82].

The ageing population in high-income countries has led to a rise in falls-related TBI. In lower-income countries, increased access to motor vehicles has driven the number of RTC-related TBIs up. Across the board, improvement in acute care has significantly increased the survival

rate following TBI, subsequently triggering an increase in the number of people living with consequences of TBI, and potentially significant rehabilitation needs [5].

TBI is a growing phenomenon globally, therefore carrying significant social and economic burdens [9]. In 2011, Gustavsson et al. reviewed the costs of brain disorders in Europe [83]. TBI costs were the 8th highest of 19 reviewed conditions, estimated to be more expensive than stroke. This is because people affected by TBI are largely people of working age and the societal production losses are much greater than those in conditions primarily affecting older people, such as stroke. However, as pointed out by Marmot, "health should not be the means to the ends of a stronger economy. Surely the higher goal should be health and wellbeing" [84, p.17].

REHABILITATION PATHWAYS

TBI has historically been perceived as a self-limiting injury. In recent years however, a shift in understanding of pathophysiology and recovery patterns suggests that TBI may be approached as a long-term condition requiring some level of intervention and monitoring in a rehabilitation context.

Rehabilitation is defined by the British Society of Rehabilitation Medicine as "a process of active change by which a person who has become disabled acquires the knowledge and skills needed for optimal physical, psychological and social function" [5]. The first step of any rehabilitation programme is the identification of the patient's needs [85]. From these, restoration and compensation strategies are put in place in order to reach optimal functioning and ensure proper social reintegration of patients [86-88]. As such, rehabilitation is a long-term process, which starts from the acute stages of care and supports recovery through to community settings (Figure 1.5).

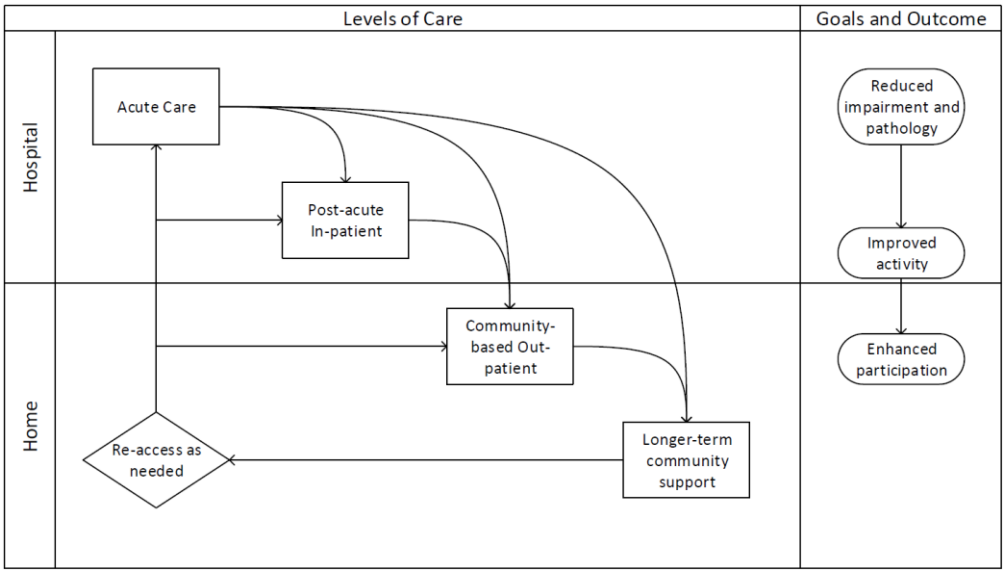


Figure 1.5. Slinky Model of Rehabilitation

(adapted from Royal College of Physicians, 2003 [5])

The rehabilitation picture for TBI is complex due to the heterogeneity of both the patient population and the nature and severity of P-TBI-S. Neurorehabilitation is multidisciplinary, with core specialties including occupational therapy, physiotherapy, speech and language therapy and neuropsychology [5]. Adding to the challenge of TBI rehabilitation is the propensity of TBI to occur in a polytrauma context. Indeed, it is estimated that around 35% of TBI cases suffer concomitant extra-cranial injuries [89,90].

As such, an efficient neurorehabilitation programme necessitates good communication between different services and specialists, to ensure that patients receive comprehensive and coordinated care [91].

In this thesis, 'care pathways' will denote defined care routes, governed by guidelines or protocols. 'Care journeys' will denote the patients' natural trajectories of care.

In spite of the apparent crucial role of organised coordinated rehabilitation for people with TBI, clinical guidelines are scarce and generally non-specific. For example, the National Institute for Health and Care Excellence guideline for the assessment and management of head injury simply recommends that "there [be] an opportunity available for referral from primary care to an outpatient appointment with a professional trained in assessment and management of sequelae of brain injury" [26, p.39].

Considering the complexity of TBI and TBI care, and the epidemiological scale of the problem, it is not surprising that the development of comprehensive rehabilitation services to remedy the current lack of a coordinated rehabilitation network is at the forefront of

international healthcare resolutions [56,85]. Effective multidisciplinary coordination requires significant planning and communication to become seamless.

However, different services may have different agendas and organisational systems. They might use performance indicators that include items beyond the delivery of the best possible care alone (i.e. cost, patient flow, staffing).These factors constitute barriers to collaborative working, and ultimately may be detrimental to the patients in spite of best intentions. [92]

At the same time, the development of coordinated care is at the forefront of the healthcare agenda [93,94]. In 2015, the NHS England launched a new care models programme.

The aim of this programme was to trial 5 different models in vanguard sites for a potential redesign of health and care systems: multispecialty community providers, integrated primary and acute care systems, enhanced health in care homes, urgent and emergency care, and acute care collaboration.

The aim of this redesign was to promote stronger community-based care and enhance the links between different services. Initial evaluation of these vanguards are promising, although it may be too early to judge on the feasibility of widespread development [94,95].

CONCLUSIONS

Following uncomplicated Traumatic Brain Injury (TBI), a non-negligible minority of patients experience protracted recovery, which has serious implications for their functional social re-integration. The paucity of clinical guidelines overseeing the rehabilitation of these individuals has been highlighted as problematic in the literature. Healthcare systems for TBI patients are complex to navigate, adding to poor access to care for this patient population. Moreover, the cognitive deficits characteristic of TBI may make it difficult for patients to recognise their own functional struggles and seek appropriate support. As a consequence, many patients with Post Traumatic Brain Injury Syndrome (P-TBI-S) fall through the gaps of healthcare.

Calls for research around rehabilitation care pathways and service provision for people with TBI have been recurrent in the last two decades [3,6]. Methodological shortcomings of the literature have been pointed at as a major cause of these knowledge gaps. Indeed, the variability of TBI and its definitions, its consequences, and the vast range of individuals it affects constitute significant barriers to the production of generalizable studies.

The overarching aim is to define robust care pathways for people with P-TBI-S. The 3-step Donabedian model [96] for the evaluation of quality of care was used as framework to guide the development of the work presented in this thesis (Figure 1.6).

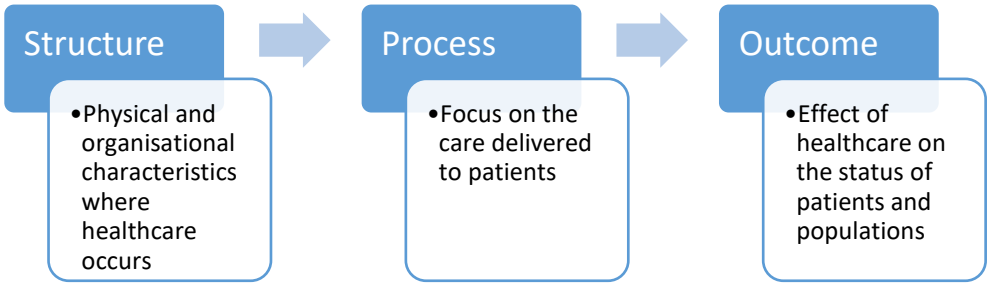


Figure 1.6. Donabedian model for quality of care

(adapted from NHS Improvement[97])

The work presented in this thesis set out to address three objectives linked to the Structure and Process components of the Donabedian model:

1. Understand the state of rehabilitation care for this patient population.
2. Identify core elements of a care pathway for people with P-TBI-S.
3. Propose new avenues to explore care journeys in large and varied samples.

Different research questions were defined to address these objectives. These questions and their relationship to the research objectives are presented in Table 1.4. Findings from this work will pave the way towards future exploration of the outcomes of care for people with persisting symptoms following TBI, thus completing the Donadebian model.

Table 1.4. Links between research questions and research objectives

Questions / **Objectives**	Understand the state of rehabilitation	Identify core elements of a care pathways	Propose new avenues to explore care journeys
What are care pathways for the rehabilitation of people with P-TBI-S?	✓	✓	
What are the care journeys for people with P-TBI-S?	✓	✓	
What methodological approaches are used to explore care journeys?	✓		✓
What are the needs of people with TBI (and P-TBI-S) at different stages of care?	✓	✓	
What range of stakeholders and services play a role in patients' care journeys?	✓	✓	
What is the nature and extent of patient education about P-TBI-S at discharge from acute care?	✓		
What advice if given about access to further support for P-TBI-S?	✓		
Are there local care pathways for people with P-TBI-S?	✓	✓	
What are the typical care journeys for people with mild TBI in the local area?	✓	✓	
What should local care provision for this patient group look like?		✓	
What features would be useful to people with P-TBI-S in a mobile app for self-management?			✓
Would the use of a mobile app for research purposed be acceptable to people with P-TBI-S?			✓

CHAPTER 2 - RATIONALE AND METHODOLOGY

In this chapter, different methodologies will be explored in order to select the most appropriate methods to answer the research questions outlined in Chapter 1. In particular, different literature review methods as well as approaches to primary research (quantitative, qualitative, and mixed methods) will be discussed.

Research objectives

1. Understand the state of rehabilitation care for this patient population.
2. Identify core elements of a care pathway for people with P-TBI-S.
3. Propose new avenues to explore care journeys in large and varied samples.

THESIS STRUCTURE

This project is divided into 3 parts (Figure 2.1). Part I consists of a review of the literature to: explore the state of and views about rehabilitation for people with P-TBI-S; identify care pathways for this population; and highlight any elements to help define a robust care pathway. Part II builds on findings from the review of the literature and sets out to explore approach to rehabilitation for people with P-TBI-S at a national and local level. Part III proposes a new avenue to support the journey to recovery of people with P-TBI-S, and sets out a basis for more large-scale research on care and support services for this population.

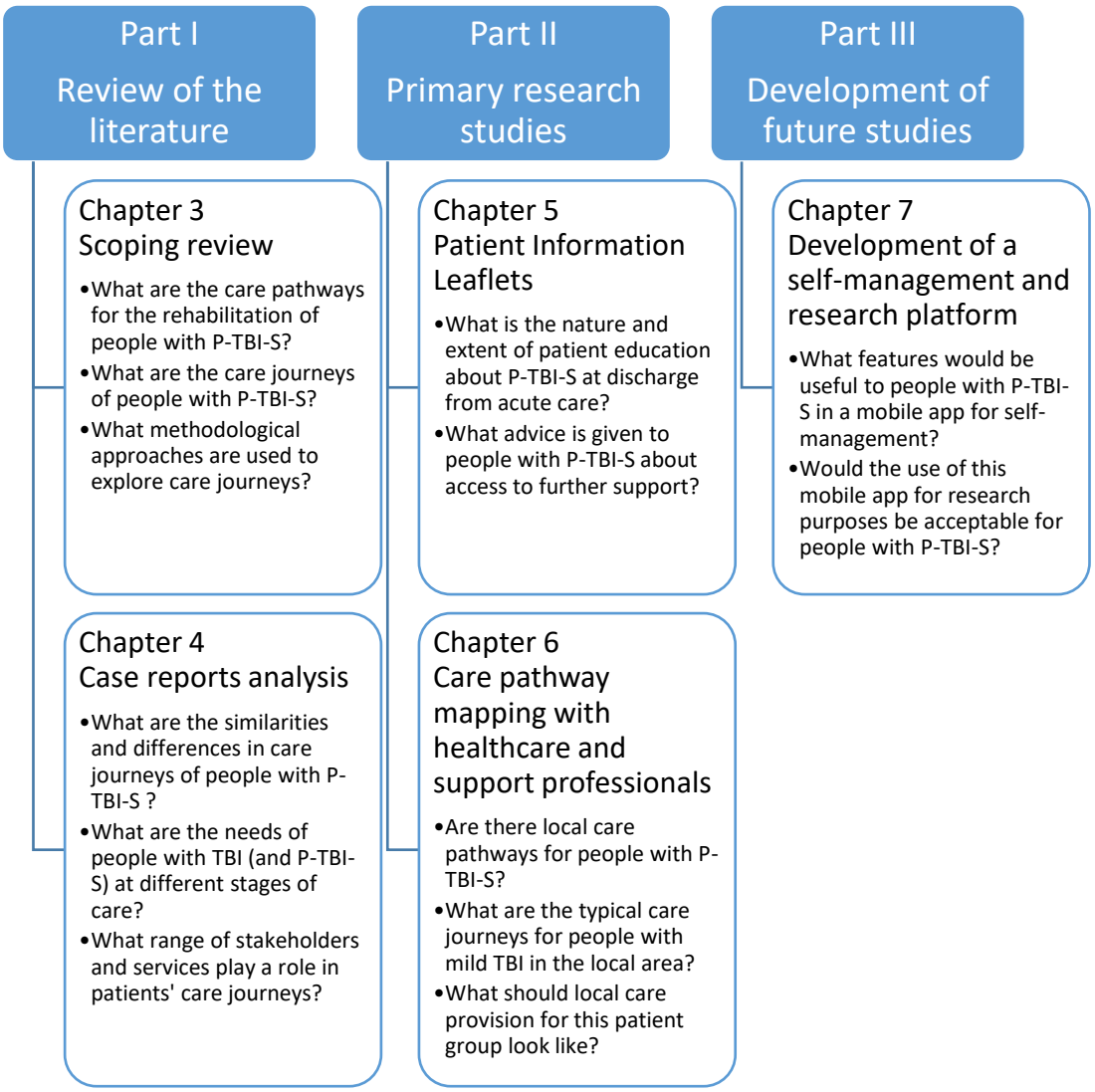


Figure 2.1. Thesis structure and research questions

METHODOLOGY

The research objectives and questions defined in this thesis are interlinked and can be explored using different but complementary approaches (Table 2.1). In this section, different approaches, broadly divided into literature review and primary research options, are presented.

Table 2.1. Research questions and methodological approaches

Questions \ Approaches	Review of the literature	Primary research
What are care pathways for the rehabilitation of people with P-TBI-S?	✓	✓
What are the care journeys for people with P-TBI-S?	✓	✓
What methodological approaches are used to explore care journeys?	✓	
What are the needs of people with TBI (and P-TBI-S) at different stages of care?	✓	✓
What range of stakeholders and services play a role in patients' care journeys?	✓	✓
What is the nature and extent of patient education about P-TBI-S at discharge from acute care?	✓	✓
What advice if given about access to further support for P-TBI-S?	✓	✓
Are there local care pathways for people with P-TBI-S?		✓
What are the typical care journeys for people with mild TBI in the local area?		✓
What should local care provision for this patient group look like?	✓	✓
What features would be useful to people with P-TBI-S in a mobile app for self-management?		✓
Would the use of a mobile app for research purposed be acceptable to people with P-TBI-S?		✓

Review of the literature

A first possible approach to address the objectives of this project is a review of the existing literature in search of evidence regarding current care pathways, patient care journeys, the views of different stakeholders about rehabilitation for people with P-TBI-S as well as methodological approaches used in primary research to examine these different elements.

Numerous review methods exist, each suited to specific aims. In 2009, Grant and Booth identified 14 main review types with different search, appraisal, synthesis and analysis approaches in in healthcare fields [98]. These main review types and their aims are presented in Table 2.2.

Table 2.2. Review types

(adapted from Grant & Booth, 2009 [98])

Note: This table excludes 'overviews' and 'literature reviews', which are both generic terms describing any review of the literature.

Review type	Aim
Best evidence synthesis	Review combining critical review and systematic review approaches to generate practice recommendations
Critical review	Extensive exploration of literature including a critical evaluation of the quality of evidence. Aims at identifying contribution to an existing or new theory.
Mapping review	Review mapping/categorising the existing literature to identify research gaps.
Meta-analysis	Review which statistically integrates the findings of quantitative studies.
Mixed methods review	Review which integrates findings from different types of studies (i.e. quantitative and qualitative).
Qualitative synthesis	Review which thematically integrates the findings of qualitative studies.
Rapid review	Review based on a systematic review methodology, but which falls short in terms of search comprehensiveness and/or quality assessment because of time constraints.
Scoping review	Assessment of size, scope, nature and extent of available literature. Often used to define the parameters of a further review.
State-of-the-art review	Review synthesizing the current state of knowledge in a given area, with a focus on identifying areas for future research
Systematic review	Review which presents systematically searched for, appraised and synthesised evidence, typically adhering to a specific and transparent protocol
Systematised review	Review based on a systematic review methodology but may fall short in either search comprehensiveness, or quality assessment
Umbrella review	Review combining the evidence from existing reviews.

In the context of this thesis, the review of the literature aims at synthesising information about both the contents of care pathways and journeys, the existing approaches used to explore these, and the methodological limitation they face.

It is unclear what the size or the nature of the relevant body of literature might be. The overview presented in Chapter 1 suggests that little research about care pathways has been conducted. As such, this review should be both wide in its inclusion criteria (i.e. be inclusive of research using a variety of methods) and as comprehensive as possible in its search process, to ensure that any relevant literature is captured. Therefore, review types that do not include comprehensive search of the literature (i.e. rapid reviews, systematised

reviews) and those that exclude certain types of literature (i.e. meta-analyses, mixed methods reviews and qualitative syntheses) are not appropriate in the context of this thesis.

Critical reviews and best evidence syntheses have a prerequisite for some indication that a substantial amount of relevant research is available. In the context of care pathways for people with P-TBI-S, it appears that little information is available (Chapter 1), which makes those methodological approaches unsuitable for this work.

State-of-the-arts reviews focus on current knowledge and planning for future research but tend not to evaluate historical research. As one of the aims for the review proposed in this thesis is to identify potential methodological shortcomings in the field, a state-of-the-arts approach is not suitable.

The main aim of a mapping review is to identify research gaps, however, as the review objectives in this thesis include an overview of knowledge about rehabilitation pathways, a mapping review would not be appropriate.

A systematic review is the best-known type of review. Systematic reviews are based on strict and transparent protocols which allow for replication and updating overtime. However, these reviews typically strictly limit inclusion criteria (i.e. single study type, specific population samples) in order to homogenize the information synthesized and draw more generalizable conclusions. In the context of this thesis, a systematic review approach does not seem appropriate as the lack of knowledge about the makeup of the relevant literature is still unclear. This would render the development of a strict systematic protocol difficult and run the risk of the review resulting in the inclusion of a very limited number of papers.

With all these elements taken into considerations, a scoping review methodology seems most appropriate in this context. A scoping review proposes an overview of the literature both in terms of past and current knowledge, knowledge gaps, and methodologies. This type of review aims for a large scope exhaustive search of the literature: it is flexible enough to allow for the inclusion of a wide variety of literature including primary research studies using variable methods, as well as reviews, guidelines, opinion pieces and clinical commentaries. The quality of evidence is not formally assessed, results are summarized in a table accompanied by a narrative summary. Results are typically presented by grouping papers by study design with a focus on research methods. The analysis should characterise both the nature and extent of the knowledge on the given research topic so that suggestions for further, more specific reviews can be proposed.

Systematic reviews are central to evidence-based practice, due to their transparent, comprehensive and protocol-based nature. A typical perceived weakness of scoping reviews are their lack of rigour [99]. Scoping reviews however carry the advantage to be

inclusive of wider ranges of evidence than systematic reviews. As such, coupled with a protocol-based approach, scoping reviews can be a valuable tool. The Joanna Briggs Institute proposes a methodology for the development of such scoping reviews [100], drawing on previous scoping review frameworks[101,102] to enhance clarity and rigour of the scoping review process (Table 2.3).

Table 2.3. Components of a transparent scoping review

(Adapted from The Joanna Briggs Institute, 2015 [100])

1	Review title, objectives, and questions
2	Background
3	Inclusion criteria
4	Search strategy
5	Extraction of results
6	Presentation of results
7	Conclusion

A scoping review of the care pathways and care journeys for people with P-TBI-S will provide an understanding of the state of rehabilitation for this patient population. It is expected that few studies will specifically look at care pathways and care journeys, as this area has been highlighted as a significant research gap in the field [3,103]. However, it is possible that elements of these are reported coincidentally. It is expected that different studies will highlight different elements of a care pathway, or describe pathways in more narrow timeframes and settings (i.e. exploring patient care in acute settings). The scoping review will also allow for an account of the different methods used to explore care pathways and journeys, including potential shortcomings or barriers for further exploration. These will be used as a basis for the proposal of new avenues for research in this area. In addition, this review may highlight existing studies using methods that are not typically considered to lead to high levels of evidence (Figure 2.2). The scoping review is presented in Chapter 3, and a detailed analysis of extracted case reports is presented in Chapter 4.

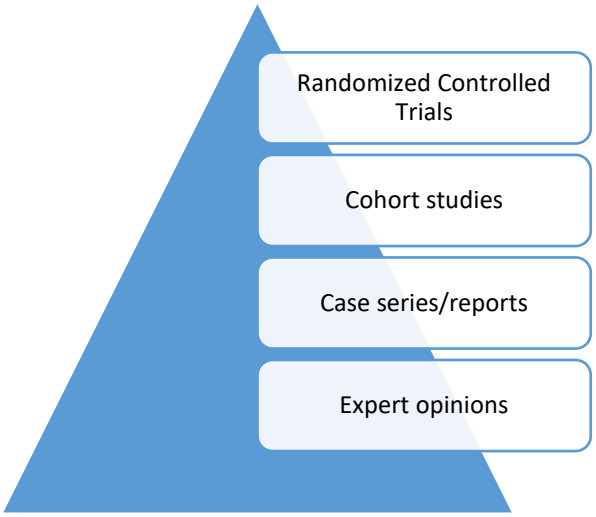


Figure 2.2. Levels of evidence for Evidence-Based Medicine

Top to bottom: higher to lower levels of evidence sources

(adapted from Burns et al, 2011 [104].)

Primary research

Beyond a review of the literature, the objectives of this project may be explored through primary research studies.

Research objectives

4. Understand the state of rehabilitation care for this patient population.
5. Identify core elements of a care pathway for people with P-TBI-S.
6. Propose new avenues to explore care journeys in large and varied samples.

Different options are available to address the research objectives, broadly divided into quantitative, qualitative and mixed-methods approaches.

Quantitative approach

A quantitative exploration of care journeys to understand the current state of rehabilitation for people with P-TBI-S could be carried out through an analysis of their healthcare records. This would allow for the collection of a vast amount of data which could be used to highlight trends in the nature and extent of service use by this patient group. The convergence of patient journeys towards particular services along their journey could highlight potential core elements of a care pathway.

However, this approach faces a number of challenges in the current context. Firstly, it would rely on the accessibility of thorough patient notes across a potentially large number of services extending across the boundaries of different governing bodies (i.e. different NHS

trusts, different CCGs). Moreover, this approach would not allow for the capture of services that fall beyond the remit of the healthcare system. Another barrier to this approach is that it would imply that P-TBI-S is systematically detected, recorded and coded by the healthcare system. This is unlikely given the variable definitions and presentations of both mild TBI and P-TBI-S. A quantitative analysis of patient records would require recruitment of patients at different levels of care (i.e. brain injury clinics, A&E department, GP surgeries) to ensure that all patients with P-TBI-S accessing healthcare services are represented. This assumes that there is already a clear understanding of the variety of care journeys, so that key sources of P-TBI-S patients are not excluded by design. Beyond these concerns, the sole use of patient records to evaluate the state of rehabilitation is unlikely to provide information pertaining to decision-making processes and the factors influencing those decision, which are critical to understand the causes of any variation in care journeys.

Therefore, although a quantitative evaluation of care for people with P-TBI-S through examination of healthcare records would be valuable, critical elements enabling its implementation are still missing at this stage, and it could not stand alone to propose a comprehensive understanding of rehabilitation for this patient group.

Qualitative approach

Qualitative research approaches present a number of advantages that make them particularly well suited for health science research [105]. Firstly, qualitative approaches may be used when quantitative approaches do not fit the problem. This is not an uncommon situation in health science, of which the inherent social components lead to the issues of interest often comprising complex concepts that may not be easily measured [106]. As discussed previously, the objectives and questions defined for this work do not lend themselves to (exclusively) quantitative exploration because of a currently limited understanding of the context of rehabilitation for people with P-TBI-S. Although valid, placing the use of qualitative research as an alternative to otherwise preferred but contextually inappropriate quantitative methods may well highlight a pervasive judgement of the value of research methodologies based on the hierarchy of evidence dominating evidence-based medicine.

Qualitative approaches present unique advantages which can both complement and supplement work anchored in quantitative methods. Qualitative method sallow for a deep exploration of contextual factors that not only guide the development of quantitative studies, but allow quantitative results to be scrutinized through a more holistic lens. Qualitative methodologies can be used to explain mechanisms underpinning causations, develop new and refine existing theories, and allow for dynamic changes in perspectives

because of the flexibility they afford [107]. Five core qualitative methodological approaches are presented in Table 2.4.

Table 2.4. Approaches to qualitative research

(Adapted from Creswell, 2013 [105])

	Focus	Aim
Narrative	Individual stories	Reporting individual experiences, typically involving some chronological perspective
Phenomenological	Shared experience or understanding of an object	Describe an object common to several individuals
Grounded theory	Individuals understanding of an object	Propose a unified theoretical explanation shaped by the views of participants about an object
Ethnographic	Factors affecting individuals understanding of an object	Similar to grounded theory but with added focus on participants shared cultural context
Case study	Single case anchored in a specified context and setting	Report on a single case or use of a single case to illustrate the understanding of a broader object.

Two of the objectives of this project lend themselves to qualitative approaches. Gaining the perspectives of healthcare and support providers and people with P-TBI-S is important to both understand the state of rehabilitation and to identify core elements of a care pathway. Both case study and narrative approaches have the potential to generate high levels of detail, but remain confined to individual contexts. As such, these approaches are unlikely to lead to a general understanding of current and ideal care for people with P-TBI-S. Grounded theory and ethnographic approaches assume the researcher approaches the object of study without preconceived notions. These approaches were not considered appropriate in this thesis because the qualitative investigation of the object of the study, care for people with P-TBI-S, will directly build on findings from the review of the literature. The purpose of conducting the literature review first was to tailor the interview topic guide to home in on areas of the care processes previously highlighted as problematic. Therefore, the qualitative studies designed to address the objectives of this thesis are anchored within a phenomenological framework. With a phenomenological approach, the understanding of care pathways and journeys is formed through a combination of prior understanding (acquired through the review of the literature) and information extracted from interviewing Health Care Professionals. The results presented in this thesis there represent the shared understanding of care pathways and care journeys.

The initial aim was to collect two sets of qualitative data with two main stakeholder groups: people who have sustained a mild TBI and subsequently experienced P-TBI-S, and healthcare and support professionals who are involved in the care of these people. In both cases, a focus group approach was dismissed in favour of one-to-one semi-structured interviews. For the healthcare and support professionals, a focus group would enable reasoning in terms of multi-disciplinary teams, and better reflect the coordinated organisation of care. However, it also carries logistical time-related pitfalls, as a focus group may need to be particularly lengthy in order to reach a satisfying level of detail. This was deemed problematic for an already stretched healthcare workforce. For that reason, a one-on-one interview approach was preferred, with the inclusion of trauma coordinators, to retrieve information regarding multi-disciplinary care coordination. This trade-off may however increase logistical constraints for the researcher as a potentially high number of interviews may need to be conducted to capture all the stakeholders of care provision. The current knowledge of patients' care journeys, and by extension the lack of knowledge about the care providers they may be interacting with are limited. Therefore, it is possible that some key stakeholders may not be identified in the initial study design. This challenge should be mitigated by generating a list of roles to be interviewed through findings from the review of the literature, and through a snowball sampling technique for recruitment into the study.

Similar logistical concerns led to the favouring of one-on-one interviews over focus groups for the collection of patient data, particularly considering the cognitive and emotional difficulties people with TBI are likely to face. In addition, the heterogeneity of TBI is likely to lead to substantially different care journeys from one participant to the next, therefore questioning any benefits that a focus group approach would bring forth. Within the context of these studies, the main criteria for choice of a qualitative approach was the potential for variation mapping, and the capacity for the capture of high levels of detail. As such, the use of qualitative semi-structured interviews is a suitable approach as it generates rich information that can be analysed using multiple methods.

Recruitment of people with P-TBI-S proved particularly challenging: only one patient could be interviewed for this study, and results are not reported in this thesis. A detailed discussion on the challenges of this study is presented in Chapter 8. Chapter 6 presents the study conducted with healthcare and support and support professionals.

The exploration of care pathways using a qualitative approach confined within relatively narrow geographical boundaries will inevitably anchor findings to the local area. This may constitute an important barrier to its use as the basis of a wider, more quantitative exploration of care pathways. However, the complexity of NHS and CCG commissioning,

local variations in service provision and limited timeframe of this project would have not allowed for a sufficiently detailed mapping of care pathways.

In this thesis, a qualitative analysis of educational materials about mild TBI distributed to patients in England is also presented. This study, presented in Chapter 5, explores educational materials distributed to patients with mild TBI at discharge from A&E departments across the different Major Trauma Networks in England. The aim was to explore the nature, extent and variability in advice given to patients about seeking support should they experience persisting symptoms.

Mixed-methods and beyond

Quantitative and qualitative approaches need not be opposed. They do not necessarily represent discrete categories. The overarching aim of this project is to define care pathways for people with P-TBI-S. A mixed-methods approach, combining elements of both quantitative and qualitative research techniques, is best suited to achieve this aim, as it allows for both breadth and depth of the understanding of the current rehabilitation provision and its shortcomings [108].

While the research presented in this thesis is mainly anchored in qualitative approaches, the penultimate chapter presents the initial steps towards the development of a new and more quantitative approach to research on care journeys. This work afforded the opportunity for the involvement of expert patients to participate in the co-development of future research (Chapter 7). Patient and Public Involvement (PPI) is central to health and social care policy development in the UK and empowers individuals to become central actors in shaping services.

> *"You have the right to be involved, directly or through representatives, in the planning of healthcare services commissioned by NHS bodies, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services."*
>
> NHS Constitution [109, p.9]

A PPI approach was adopted for this research development work, to ensure that the future studies align with the concerns of people with brain injury, and that any tools developed for this work are both relevant and acceptable by the people who will use them.

RESEARCH GOVERNANCE AND FUNDING

This PhD was funded through the Warwick Medical School Scholarship. Ethical approval the Health Research Authority Research Ethics Committee (REC reference: 19/NI/0014, IRAS project ID: 248707).

CONCLUSIONS

In this chapter, different methodological approaches to research were explored in order to select those most appropriate methods to address the objectives of this thesis:

1. Understand the state of rehabilitation care for this patient population.
2. Identify core elements of a care pathway for people with P-TBI-S.
3. Propose new avenues to explore care journeys in large and varied samples.

Five studies were designed to address those objectives and are presented in Chapters 3 to 7 (Figure 2.3).

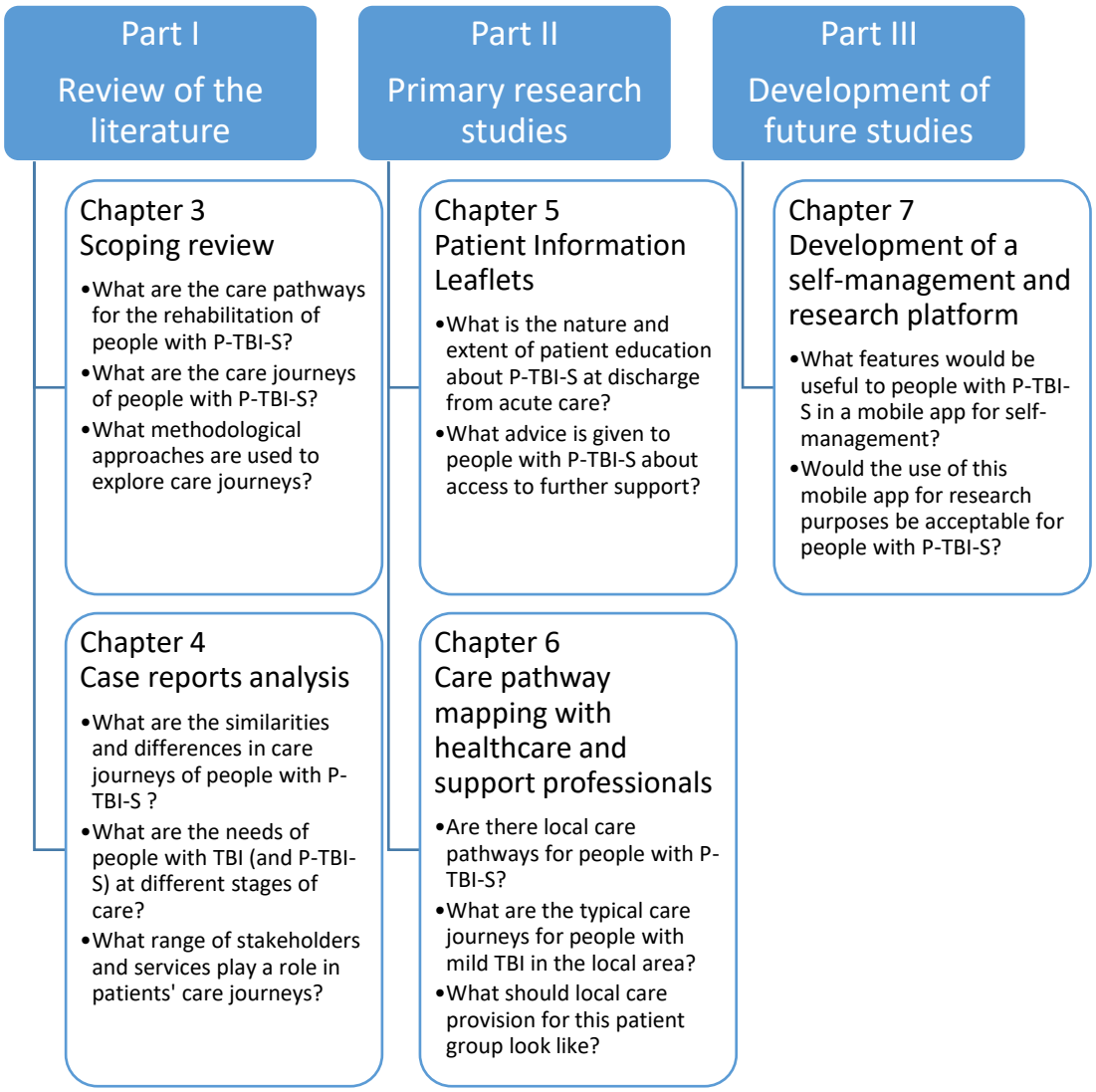


Figure 2.3. Thesis structure and research questions

Part I: Review of the literature

Traumatic Brain Injury (TBI) is complex and heterogeneous. Whereas milder TBIs are typically self-limiting, a non-negligible minority of patients do not follow the typical recovery trajectory, and experience lasting symptoms as part of a Post Traumatic Brain Injury Syndrome (P-TBI-S).

The overarching aim of this thesis is to define robust care pathways for people with P-TBI-S. Within this, Part I sets out to explore the literature to examine the current state of rehabilitation provision for this patient population; understand the current views about rehabilitation for this group; describe existing care pathways; and identify factors that could inform future development of care pathways.

An initial overview of TBI care highlighted a lack of specific guidelines and recommendations for patients with P-TBI-S. This is surprising as P-TBI-S is not a new concept [110]. As such, one would expect care pathways for P-TBI-S to be a well-developed area of rehabilitation medicine. It is possible that the lack of practice guidelines stems from a lack of high level, generalizable research required for the production of evidence-based recommendations in this area.

Part I consists of two chapters exploring the P-TBI-S rehabilitation literature to answer 6 research questions:

1. What are the care pathways for the rehabilitation of people with P-TBI-S?
2. What are the care journeys for people with P-TBI-S?
3. What methodological approaches are used to explore care journeys?
4. What are the similarities and differences in care journeys of people with P-TBI-S (using case reports)?
5. What are the needs of people with TBI at different stages of care?
6. What range of stakeholders and services play a role in patients' care journeys?

Chapter 3 presents a large scoping review exploring a variety of evidence contributing to the current understanding of care pathways and care journeys for people with P-TBI-S. Chapter 4 presents a detailed analysis of the case reports identified in the scoping review. Information pertaining to care journeys and P-TBI-S was extracted and discussed through the lenses of the Royal College of Physicians' slinky model of rehabilitation and the International Classification of Function, Disability and Health.

CHAPTER 3 – SCOPING REVIEW

In this chapter, a review of the existing literature around care for people with Post Traumatic Brain Injury Syndrome (P-TBI-S) is presented. A scoping review methodology is used to capture a wide range of evidence and establish whether and to what extent both care pathway and care journeys for this patient group have been studied.

Figure 3.1 highlights the place of this study within the broader structure of this thesis.

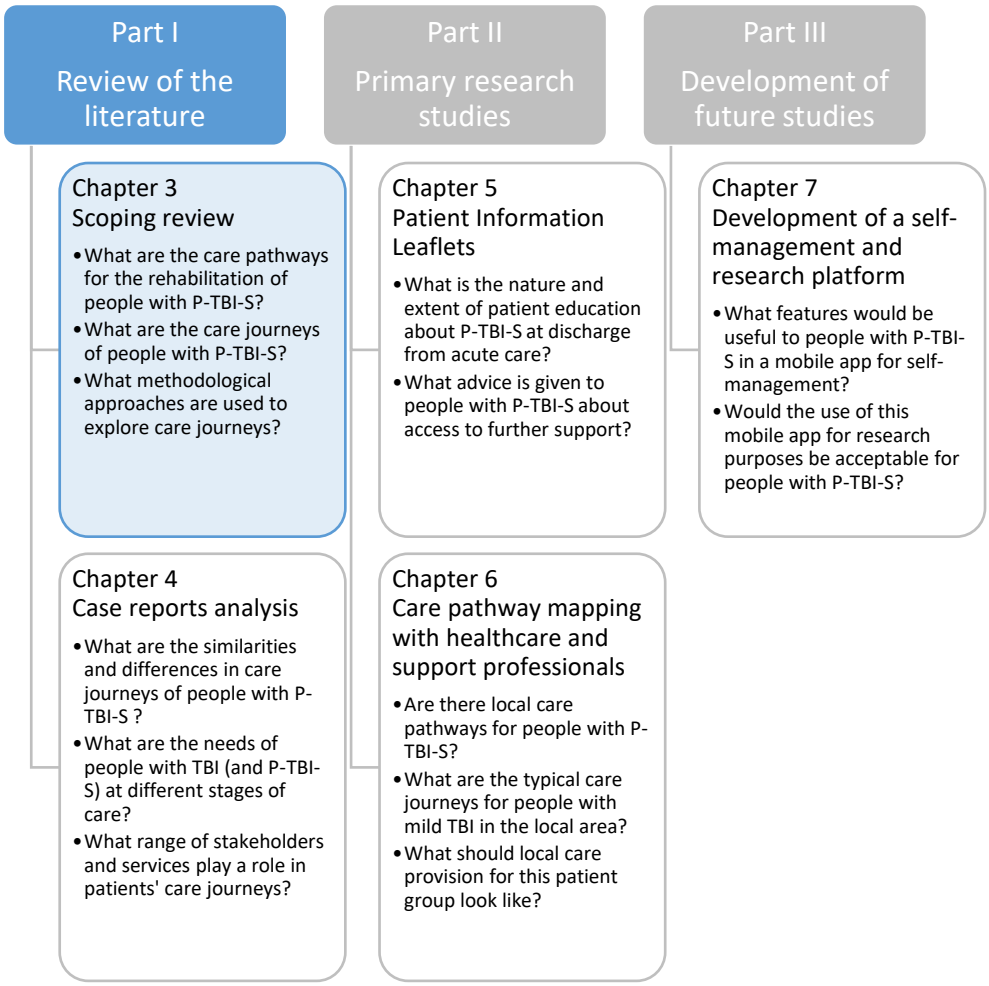


Figure 3.1. Chapter 3 within thesis structure

BACKGROUND

Traumatic Brain Injury (TBI), especially in its milder form, is generally understood to be a self-limited condition, of which the somatic, cognitive and emotional sequelae resolve within a few days to a few weeks of injury. In a significant minority of cases however, TBI symptoms persist beyond the typical recovery frame and can have serious implications for patients' re-integration into the community [111]. The rehabilitation needs and evaluation of service provision for this group are under-explored areas in the TBI literature [3,6]. Although

evidence supporting the existence of persisting symptoms following TBI has been present in the TBI literature since the 19th century, controversies, particularly surrounding its aetiology, persist [112].

The heterogeneity in TBI, manifestations of subsequent symptoms, and the patient population, are regularly used to justify the lack of unified rehabilitation guidelines [3,6]. In the context of evidence-based medicine, the production of clinical guidelines relies on results from high-level studies, which particularly favours meta-analyses of randomized controlled trials [104]. However, the heterogeneity of TBI has led to few comparable studies that would contribute to this 'golden' evidence base. Moreover, a common stance is that "no two TBIs are the same and, consequently, no two treatment programmes can be identical" [113, p.443]. This view of TBI as highly individual has resulted in few care guidelines for this patient group (Chapter 1).

At the same time, it is recognised that the 'miserable minority' [114] of TBI survivors with persisting symptoms are at high risk of falling through the gaps of healthcare [115,116], which can have serious consequences including relationship breakdowns and loss of employment [117]. It appears therefore, that there may be value in some level of overarching guidance regarding care for people with P-TBI-S.

RESEARCH OBJECTIVES

The following review aimed to explore the literature to understand the state of rehabilitation for people with P-TBI-S. Three research questions guided this review:

1. What are the care pathways for the rehabilitation of people with P-TBI-S?
2. What are the care journeys of people with P-TBI-S?
3. What methodological approaches are used to explore care journeys?

METHODS

A scoping review method was used to examine care pathways and journeys for people with P-TBI-S [100]. This method draws upon previous scoping review frameworks and provides a detailed step-by-step approach to enhance the clarity and rigour of the review process [101,102] (Chapter 2).

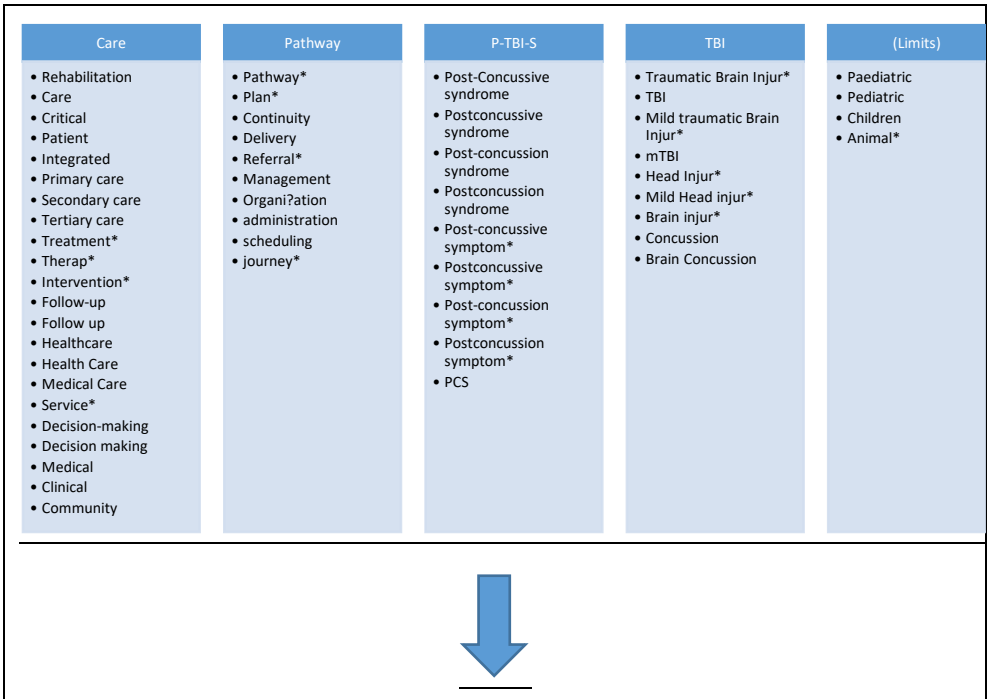
TERMINOLOGY

'Care journeys' are defined as trajectories of care, including the healthcare services and other support services (i.e. social care, charity support) accessed by the patient. 'Care pathways' are defined as guideline or protocol driven care routes.

P-TBI-S was determined using each author's definition of persisting symptoms (often 'Post-Concussion Syndrome (PCS)' or 'Persisting PCS') where available. Where this was not explicitly mentioned, discussion of any atypical recovery (i.e. recovery not within the expected recovery timeframe for mTBI) in conjunction with classic post-TBI symptoms of any severity was considered P-TBI-S.

SEARCH TERMS AND DATABASES

PubMed, Web of Science, CINAHL, Embase, AMED, and the Cochrane library were searched on 4th January 2019, using a combination of search terms relating to care pathways and journeys, P-TBI-S and TBI. The search terms and a Boolean example used in PubMed are presented in Figure 3.2. Detailed search terms and search terms combinations (booleans) are presented in Appendix 3.1 and Appendix 3.2.



((traumatic brain injur* OR TBI OR Mild Traumatic Brain Injur* OR mTBI OR head injur* OR mild head injur* OR brain injur* OR concussion OR brain concussion) AND (post-concussive syndrome OR postconcussive syndrome OR post-concussion syndrome OR postconcussion syndrome OR post-concussive symptom* OR postconcussive symptom* OR post-concussion symptom* OR postconcussion symptom* OR PCS) AND (rehabilitation OR care OR critical OR patient OR integrated OR primary care OR secondary care OR tertiary care OR treatment* OR Therapy OR intervention* OR follow-up OR follow up OR healthcare OR health care OR medical care OR service* OR decision-making OR decision making OR medical OR clinical OR community) AND (pathway* OR plan OR planning OR continuity OR delivery OR referral* OR management OR organisation OR organization OR administration OR scheduling OR journey*) NOT (animal*) NOT (children OR paediatric OR pediatric))

Figure 3.2. Search terms and boolean

Grey literature, in this case guidelines, was retrieved through the websites of relevant bodies and guideline repositories (i.e. Tripdatabase.com; BMJ best practice; National Institute for Health and Care Excellence).

INCLUSION AND EXCLUSION CRITERIA

The inclusion and exclusion criteria are summarized in Table 3.1.

Table 3.1. Inclusion and exclusion criteria

Inclusion	Exclusion

- Primary research studies investigating TBI care pathways/journeys either
  - Directly (primary or secondary research objective)
  - Indirectly (coincidental reporting of information regarding care pathways/journeys)
- Published or translated in full in English or French
- Published in peer-reviewed academic journals (not applied to separately retrieved guidelines)
	- Conference abstracts
	- Paediatric studies
	- Single symptom-specific interventions

All study designs were included in order to get an idea of the scope of literature relevant to the research question. Conference abstracts were excluded as they lack detail. Moreover, any full publication relating to a conference abstract would have been identified through the database search. Studies involving exclusively paediatric samples were excluded. Paediatric TBI presents a number of additional concerns, particularly those related to developmental disruption, which may lead to care pathways elements that are neither available nor relevant to adult TBI populations. Studies involving both paediatric and adult populations were included on the basis that any shared pathway was relevant to identify in this review. Studies evaluating treatment for a single symptom were excluded, as treatment of a single symptom in a single setting gives little insight into the more global syndrome management.

SEARCH PROCESS AND SECOND REVIEWER ROLE

The search process consisted of 3 steps: a preliminary search, search 1, and search 2. The preliminary stage was the initial search using a restricted number of basic search terms. The goal of this preliminary stage was to expand and refine the search terms, define the search term combinations, and define inclusion and exclusion criteria. A proportion (~20%) of the results from the first search (for which the search terms are presented in Appendix 3.1) were screened by a second reviewer (TS). The initial agreement rate was low (39%). Discussion with TS highlighted a lack of protocol clarity on the inclusion/exclusion criteria, which was determined to be the source of the low agreement rate. Following search 1, the inclusion/exclusion criteria were refined, as were the search terms, reflecting nuances in terminology identified in the screened papers.

A proportion (10%) of the results from search 2 were screened by TS at the title and abstract screening stage. The agreement rate was ~64% (and up to 82% when TS' 'unsure' labels were disregarded). All records disagreed upon (n=50) were discussed: a final decision at the title and abstract screening stage was reached following discussion for 40 papers. No agreement could be reached for a further 10 papers, which were therefore carried over to the next stage: full-text review.

TS screened 6 papers in full, with 2 requiring discussion between the reviewers to reach consensus. Following this full text review stage, 91 papers were selected for inclusion in the scoping review.

DEDUPLICATION PROCESS

As multiple databases were searches, the results included a number of duplicates. The list of papers retrieved from the databases searches were imported into Endnote X9, which was then used to generate a list of duplicates. Exact matches (records for which all the fields were exact matches) were automatically deduplicated. Records with partial match (i.e. author and title matching exactly, but different abstracts or journals) were screened manually and deduplicated as appropriate.

Following deduplication, the records with missing abstract field information were manually retrieved prior to the title and abstract screening stage. Papers selected for full-text review were retrieved prior to the full text screening stage.

DATA EXCTRACTION PROCESS

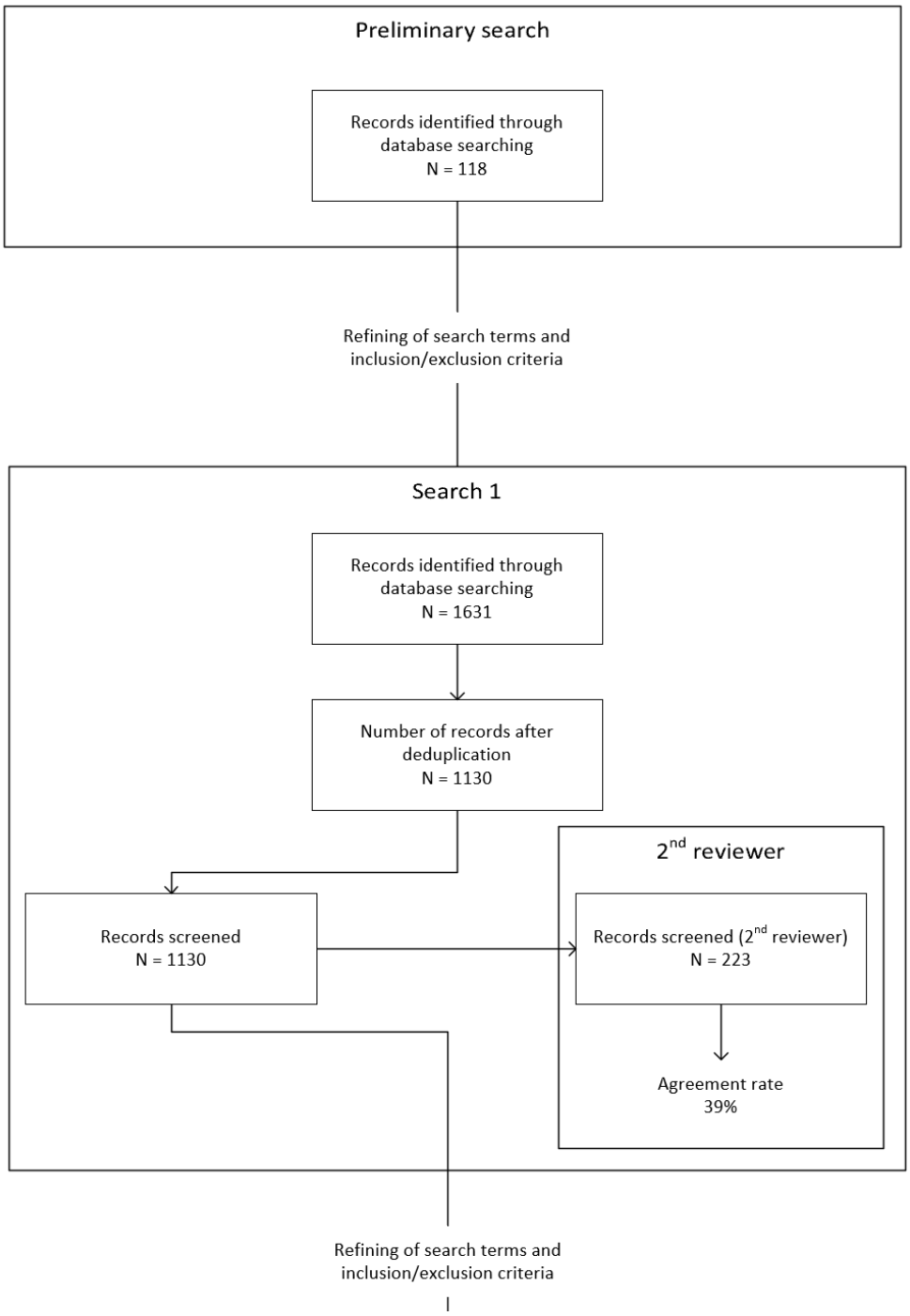
The data extracted from each paper was reported in a table and included:

- the originating country (which was inferred using the first author institutional affiliation)
- the research design
- the population of interest (general population, military, or athlete)
- sample detailed (number, age, sex)
- recruitment site
- stakeholders mentioned as part of the care journey or care pathway
- details of care journey/care pathway (including services accessed, timeframe in accessing different services, re-access to services, etc)
- author-defined typical/expected recovery from mild TBI

RESULTS

PAPER SELECTION

The database search resulted in the identification of 2008 records. In addition, 11 records were retrieved from clinical practice guidelines repositories and 14 records were identified from the reference lists of included papers. After deduplication, the titles and abstracts of 1399 records were assessed and 1152 of them were excluded. The full texts for the remaining 247 records were assessed for eligibility. 156 were excluded at this stage, and 91 were included in this scoping review. The full selection process is outlined in Figure 3.3, including details of the second reviewer involvement. The full list of included papers is presented in Table 3.2. One paper [118] presented both a case report and a cohort study, as such it appears twice in the table (ID8 and ID33).


Preliminary search
Records identified through database searching N = 118
Refining of search terms and inclusion/exclusion criteria
Search 1
Records identified through database searching N = 1631
Number of records after deduplication N = 1130
2nd reviewer
Records screened N = 1130
Records screened (2nd reviewer) N = 223
Agreement rate 39%
Refining of search terms and inclusion/exclusion criteria

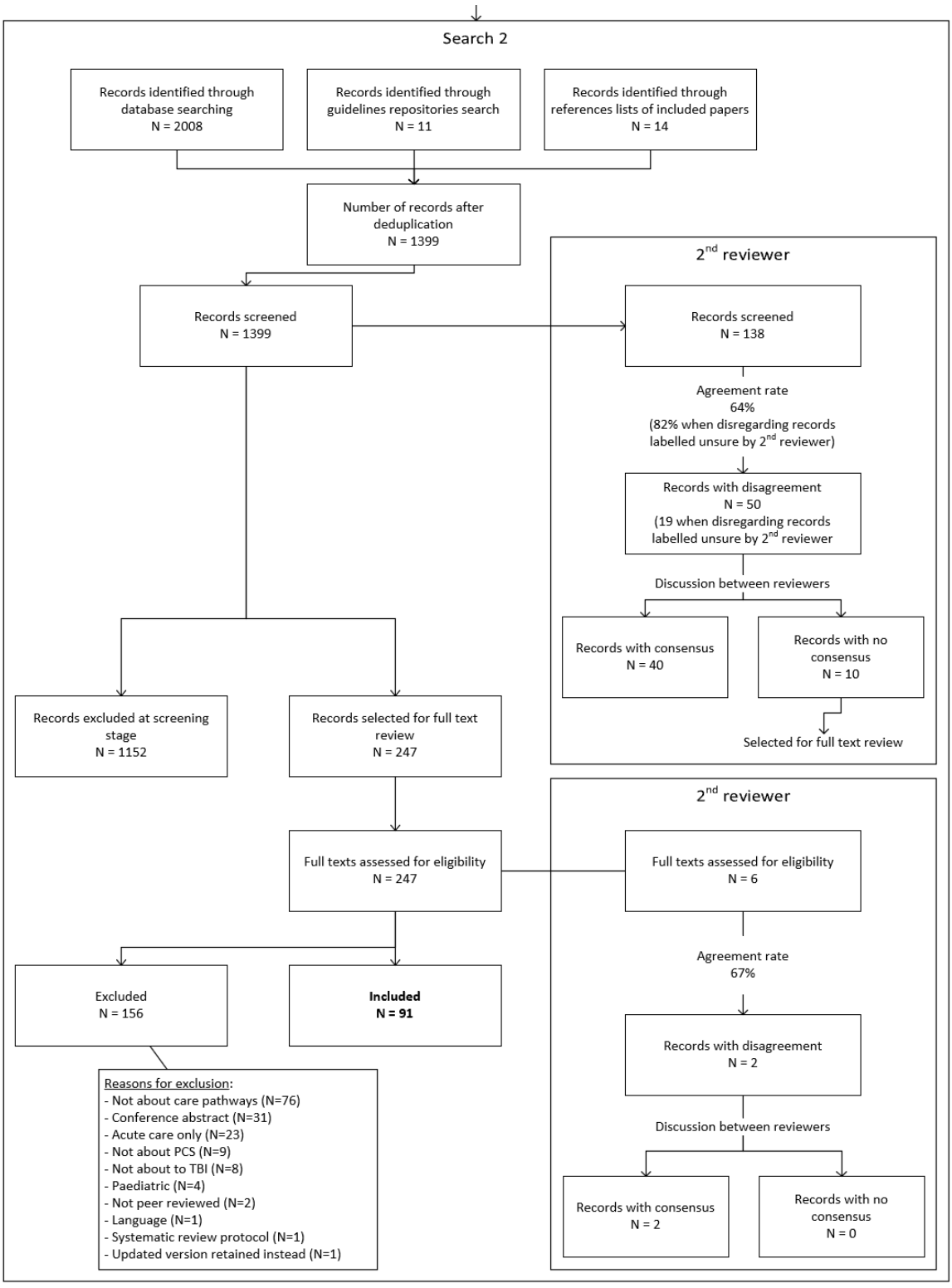


Figure 3.3. PRISMA flow diagram

Table 3.2. List of included papers

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
1	United States	Case report	General	1F, age n/s	n/s	• Colleagues • Family • Friends • General surgeon • Internist • Manager • Neurologist • Nurse • Orthopaedist • Otolaryngologist • Plastic surgeon • Psychologist	Scene → Acute → Inpatient → Home/Work → Outpatient (psychologist) → Home/Work → Outpatient (neurologist) → Home/Work 6-12 weeks post-injury to psychology, 3 months post-injury to neurology.	n/s
2	United States	Case report	General	1F, age 41	n/s	• Occupational Therapist • Neurologist	Scene → Acute → Home/Work → Outpatient (neurologist) → Out-patient (rehabilitation services) → Outpatient (occupational therapist) OT for 8 months	
3	United States	Case report	Military	1M, age 34	Multidisciplinary concussion clinic	n/s	Scene → Home/Work → Outpatient 5 months to treatment	n/s
4	United States	Case report	Athlete	1M, age 21	n/s	• Athletic Trainer • Parent • Team Physician • Teammate	Scene → AT→ Home/Work → Primary Care (team physician) → Home/Work	14
5	United States	Case report	Athlete	1F, age 20	n/s	• Academic instructors • Athletic trainer • Speech and language therapist • Team physician	Scene → Sports Med → Outpatient	10

[1] Bader & Thompson[119] (1993) The year after: post-concussion syndrome

[2] Finn & Waskiewicz[120] (2015) The role of occupational therapy in managing post-concussion syndrome

[3] Garcia-Baran et al.[121] (2016) Therapeutic approach of a high functioning individual with traumatic brain injury and subsequent emotional volatility with features of pathological laughter and crying with dextromethorphan/quinidine

[4] Hamson-Utley et al.[122] (2017) Managing mental health aspects of post-concussion syndrome in collegiate student-athletes

[5] Knollman Porter et al.[123] (2014) Speech-language pathology and concussion management in intercollegiate athletics: the Miami university concussion management program

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
6	Italy	Case report	General	1F, age 48	n/a	• neurologist	Scene → Home/Work → Acute → Home/Work → Outpatient	n/s
7	United States	Case report	General	1F, age early 50s	n/s	• Counsellor • Family • Insurance company • Neurosurgeon • Physiotherapist • Speech and Language Therapist	Scene → Home/Work → Primary Care → Outpatient (physio) → Home/Work → Primary Care → Outpatient (neurosurgery) → Outpatient (physio, SALT, counselling) → Home/Work First sought help 3d post injury, 2m at work before after initial physio and before neurosurgery consult. Neurosurgery consult 4m post-injury, insurance approval for therapy 6 months post-injury. 6m+3w post injury discharge from care against medical advice b/c insurance funding stopped	30
8	United States	Case report	General	1M, age 47	n/a	• Primary care physician • Neuropsychologist • Psychiatrist	Scene → Acute → Home/Work → Primary Care → Outpatient (psychiatrist) → ? → Outpatient (neuropsych assessment 16m post-injury) → Outpatient (cognitive therapy for 12w) → Home/Work	n/s
9	Australia	Case report	General	1F, age 24 1M, age 38	n/s	• Clinical psychologist • Neuropsychologist • Occupational therapist • Primary care physician	Scene → Home/Work → Primary Care → Home/Work → Outpatient (neuropsychologist) → Outpatient (occupational therapist) Scene → Acute → Home/Work → Outpatient (clinical psychologist) → Outpatient (neuropsychologist) → Outpatient (clinical psychologist	90
10	United Kingdom	Case report	General	1M, age 22	Neurology clinic	• Family	Scene → Acute → Home/Work → Outpatient (neurology clinic) 3 months from injury to neurology clinic consult	
11	United States	Case report	General	1F, age 50s	Clinic	• Neurologist • Neuropsychologist • Parent • Therapist	Scene → Acute → Home/Work → Outpatient (neurologist) → Outpatient (clinic) 8 months to clinic presentation	90

[6] Lambru et al.[124] (2009) Post-traumatic cluster headache: from the periphery to the central nervous system?: clinical notes

[7] Lewis & Lucas[125] (2012) Understanding mild traumatic brain injury and postconcussion syndrome

[8] Mateer[118] (1992) Systems of care for post-concussive syndrome

[9] Olver[126] (2005) Traumatic brain injury--the need for support and follow up

[10] Stone et al.[127] (2016) Functional disorders in neurology: case studies

[11] Turner et al.[128] (2018) Adapting cognitive processing therapy to treat co-occurring posttraumatic stress disorder and mild traumatic brain injury: a case study

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
12	Canada	Case series	General	435 M: 75% Age: 69% >44yo	Toronto Rehabilitation Institute Neurology service	n/s	Time from injury to clinic assessment: $\bar{X}$=23 months (71% within 1y), Median 6.8 months	n/s
13	United States	Clinical commentary	Athlete	n/a	n/a	• Physiotherapist	3 stages of management of patient with concussion: 1. Protection phase 2. Deficit management phase 3. Return to sport phase Progression of treatment is: 1. Relative rest 2. Symptom management 3. Neuroplasticity 4. Complex functional activities 5. Guided return to sport	10
14	United States	Clinical commentary	Athlete	n/a	n/a	• Athletic trainer • Neurologist • Neuropsychologist • Neurosurgeon • Primary care physician • Sport medicine physician	• Neuropsychologist=central stakeholder for care coordination. • Role of care coordinator can be filled by other qualified professionals i.e. neurosurgeon, neurologist, sports medicine physician, primary care physician. • Assessment of PCS is structured and aims to identify any pre / co-morbid factors that need to be addressed. • After the acute period, symptoms seem to align with distinct clinical trajectories that can be used to guide rehabilitation • Example UPMC Sports concussion programme offers individualised rehabilitation protocols for all athletes who have had a concussion. • Rehabilitation plans can be built using the concept of clinical trajectories so that the approach treatment is both individualised and holistic	14
15	United States	Clinical commentary	Military	n/s	n/s	• Case manager • Nurse • Polytrauma point of contact • Social worker	• Polytrauma System of care bridges the gap between acute care in military setting and VA rehabilitation centres. • Previously the patients often transitioned though private sector hospitals. Now clear pathway from in-theatre management to regional hospital in Landstuhl	n/s

[12] Colantonio & Comper[129] (2012) Post-injury symptoms after work-related traumatic brain injury in Canadian population

[13] Lundblad[130] (2017) A conceptual model for physical therapists treating athletes with protracted recovery following a concussion

[14] Reynolds et al. [131] (2014) Establishing a clinical service for the management of sports-related concussions

[15] Sigford[132] (2008) "To care for him who shall have borne the battle and for his widow and his orphan" (Abraham Lincoln): the department of veterans affairs polytrauma system of care

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
							to polytrauma rehabilitation centres, polytrauma network sites, support clinic teams and points of contact. • This came in because the injury profiles of people injured in war in the 2000s has changed, with higher levels of medical acuity and instability, complex injury patterns, high expectations of care and functional recovery from patients and families → led to specialised rehabilitation needs • Elements of re-access loops in the polytrauma system of care. • Case management (coordination of care) is critical.	
16	United States	Clinical commentary	Athlete	n/a	n/a	• Athletic director • Athletic trainer • Audiologist • Coach • Cognitive therapist • Multidisciplinary team • Neurologist • Neuro-ophthalmologist • Neuropsychologist • Neurosurgeons • Nurse • Optometrist • Physician • Psychiatrist • Psychotherapist • Speech and language pathologist • Sports physical therapist • Teacher	• Multidisciplinary team is key • Advocates for symptoms-based approach • Treatment is individualised as "no two TBIs are the same and, consequently, no two treatment programmes can be identical" (p.443) • Approach is holistic and recovery monitoring should occurs on multiple levels (school, work, social, medical, etc.)	10

[16] Stewart et al.[113] (2012) Comprehensive assessment and management of athletes with sport concussion

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
17	United States	Cohort study	General	71 (+71 matched orthopaedic controls) M:50.7%; F:49.3% Age x̄=24.04 [16, 71]	Emergency Department	• Emergency physician	• 43.7% of patients with mild head injury followed up 1 month post-injury (not significantly different from the controls) • PCS rates did not differ significantly between patients with mild head injury who followed-up and those who did not.	n/s
18	United Kingdom	Cohort study	General	305 M:72.1% Age x̄=47.5±17.6, [16, 90]	Multidisciplinary trauma clinic	• Acquired brain injury team • Allied health care professional • Charitable organisation representative • Counselling therapist • Head injury specialist nurse • Head injury specialist psychologist • Mental health crisis team • Neurorehabilitation specialist • Neurosurgery specialist • Occupational therapist • Physiotherapist • Psychologist • Speech and language therapist	<u>Acute pathway:</u> Injury Site → Hospital • 74.4% immediately • 8.6% within 24 hours • 2.3% 1-2 days • 8.2% >2d or unknown Discharge destinations from hospital: • Home 79.7% • Specialist rehab 14.5% • Unknown 5.9% <u>Rehabilitation pathway</u> Referral sources to multidisciplinary clinic*: • Neurosurgeon 40% • General/trauma surgeon 35.7% • GP 13.4% • Emergency Department phys./other 11% *referrals from secondary care more likely to be patients with moderate or severe TBI Multidisciplinary clinic median stay: 97 days [9 – 7497] Referral destinations from multidisciplinary clinic: • Charity services 100% • Further investigation (imaging, neuroendocrinology) 45.2% • Psychology 19.3% • Neuropsychiatry 18.4%	n/s

[17] Bazarian et al.[133] (2000) Minor head injury: predicting follow-up after discharge from the emergency department

[18] Bell et al.[134] (2018) Symptomatology following traumatic brain injury in a multidisciplinary clinic: experiences from a tertiary centre

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
19	United States	Cohort study	Military	100 M: 99 Age $\bar{x}$=29.9, [21, 55]	Post-deployment clinic in Polytrauma Support Clinic Team	• Primary care physician	100 post-deployment evaluation: • 33 with visual Sx • 30/33 referred to visual clinic • 23/30 evaluated + 7/30 no-show	n/s
20	United States	Cohort study	General	50 M:19; F:31 Age $\bar{x}$=36.5±10.8, [18, 61]	Neuropsychology clinic affiliated with comprehensive brain trauma rehabilitation centre	• Attorney • Physician • Rehabilitation nurse	Referral sources: • Physicians • Rehabilitation nurses • Attorneys Injury to referral $\bar{x}$=13.9 months ± 11.8, [3, 52 months] • 40% of referrals were medicolegal • 100% of sample was involved in litigation procedures	90
21	United States	Cohort study	General	199	Inpatient at level I trauma centre	• Brain injury specialist physician	• Seen at trauma centre for FU: 119/199 • Seen at rehab institute of Chicago: 7/199 (all with diagnosis of PCS and referred directly to the RIC) • Diagnosis of PCS: 20/119	n/s
22	United States	Cohort study	General	397 physicians	American Medical Association listing for each specialty of office-based non-federal physicians	• Chiropractor • Family physician • Neurologist • Neurosurgeon • Orthopaedist • Psychiatrist • Psychologist	Key referral destinations: • Cognitive rehabilitation • Pain clinic • Head injury rehabilitation unit Key referral destinations clinicians: • Psychologist • Psychiatrist • Chiropractors	n/s
23	Denmark	Cohort study	General	93,517 (935,170 reference)	Danish national hospital register	• General practice physician • Neurologist	Key services: • Emergency Department • Primary Care • Talk Therapy • Neurology	n/s

[19] Bulson et al.[135] (2012) Visual symptomatology and referral patterns for operation Iraqi freedom and operation enduring freedom veterans with traumatic brain injury

[20] Cicerone & Kalmar[136] (1995) Persistent postconcussion syndrome: the structure of subjective complaints after mild traumatic brain injury

[21] Crandall et al.[137] (2014) Patterns and predictors of follow-up in patients with mild traumatic brain injury

[22] Evans et al.[138] (1994) The physician survey on the post-concussion and whiplash syndromes

[23] Galili et al.[139] (2017) Use of general practice before and after mild traumatic brain injury: a nationwide population-based cohort study in Denmark

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
							• People with mTBI use more GP (including talk therapy) and private neurology consultation than matched controls both before and after injury. • There is a peak in service use within 3 months of injury and it takes ≈ 12 months to go back down to pre-injury level.	
24	United States	Cohort study	General	213 rehabilitation experts	American Academy of PM&R + American Congress of Rehabilitation Medicine	• Chiropractor • Counsellor • Medical doctor • Neurologist • Neuropsychologist • Neurosurgeon • Occupational therapist • Physiatrist • Physiotherapist • Psychiatrist • Psychologist • Recreational therapist • Rehabilitation nurse • Rehabilitation professional • Social worker • Speech and language therapist • Vocational counsellor	Rehabilitation disciplines that are relevant for patients with mTBI (%): • Neuropsychology: 80 • Speech pathology: 63 • Physiatry: 60 • Occupation therapy: 59 • Vocational rehabilitation: 56 • Social Service:51 • Clinical Psychology: 50 • Physical therapy: 47 • Education: 42 • Recreational therapy: 36 • Rehabilitation nursing: 35 • Neurology: 31 • Psychiatry: 26 • Neurosurgery: 10 • Chiropractic: 1 32% of survey respondents do not FU their patients. For those that do, the FU intervals are (%): • Weekly: 7 • 1-4w: 18 • 5-12w: 15 • 3-6m: 8 • 6-12m: 10 • n/s: 42 • FU are terminated after (%) • 1m: 2 • 3m: 3 • 6m: 12 • 12m: 15	n/s

[24] Harrington et al.[140] (1993) Current perceptions of rehabilitation professionals towards mild traumatic brain injury

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
							• 18m: 7 • 2y: 11 • 3y: 3 • 5y: 4 • n/s: 43	
25	United States	Cohort study	Military	473 mTBI M: 100% Age $\bar{x}$=24.4±5.3 And 656 other minor non-TBI injuries M: 100% Age $\bar{x}$=25.4±6.0	US Expeditionary Medical Encounter Database (patient who presented to forward-deployed medical treatment facilities)	• Audiologist • Cardiologist • Dentist • Dermatologist • Gastrointestinal specialist • Genitourinary specialist • Mental health professional • Neurologist • Orthopaedist • Otolaryngologist • Pulmonary specialist • Vision therapist	• No significant difference in healthcare referrals for mTBI compared to other minor injuries. • Differences in referral destinations: higher proportion of mTBI referrals to neuro services compared to other injuries. Most common referrals for mTBI: • Audiology • Neurology (significantly more for mTBI patients than patients with other mild injuries) • Mental health • Orthopaedics	n/s
26	United States	Cohort study	General	763 Age $\bar{x}$=34.8±12.9 M:64.4; F:35.6	Regional TBI centres	• Physician • Physiotherapist • Occupational therapist • Speech and language therapist • Psychologist • Peer • Vocational rehabilitation counsellor	Mildly injured used services infrequently. Most commonly used services: • Physician services • Physiotherapy • Occupational therapy • Speech therapy • Psychological services • Individual counselling • Peer support • Vocational rehabilitation • Head injury Association services Variation in access to services between different regional centres, and unrelated to proportion of patients with more severe injuries. Other factors affecting service utilisation:	n/s

[25] Heltemes et al.[141] (2012) Blast-related mild traumatic brain injury is associated with a decline in self-rated health amongst us military personnel

[26] High et al.[142] (1995) Productivity and service utilization following traumatic brain injury: results of a survey by the RSA regional TBI centers

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
							• Age (positive relationship) • Years of education (negative relationship) • Sex (women more likely to use services apart from group counselling and case management, peer support and substance abuse intervention) • Severity of injury (positive relationship)	
27	United States	Cohort study	Military	Included in analysis 257 M:89.1%; F:10.9% Age: [18,24]: 29.6% [25,29]: 22.2 [30,37]: 26.0 [38+]: 22.2 And Excluded from analysis (because of missing pre- or post- treatment data) 648 M:91.7%; F:8.3% Age: [18,24]: 34.2% [25,29]: 19.5 [30,37]: 27.3 [38+]: 19.0	TBI clinic	• Medical specialist • Neuropsychologist • Nurse practitioner • Occupational therapist • Physician • Physician assistant • Physiotherapist • Physiotherapist assistant • Primary care manager • Psychologist • Speech and language pathologist	Median time from injury to evaluation: • Included: 157 days • Excluded: 310 days Median length of treatment • Included: 50 days • Excluded: 43 days Primary Care → BAMC TBI clinic: ?TBI + ?Severity + ?Treatment recommendation → a) or b) → mTBI with persisting Sx → Multidisciplinary treatment programme with follow-up every 2 weeks, individually tailored and addressing Sx clusters. → multidisciplinary d/c → severe brain injury a/o other neurological issues → separate pathway At pre-treatment evaluation, majority of patients had 1 consult (62.7% for the included group, 69.3% for the excluded group, borderline significant)	90
28	United States	Cohort study	Military	421 (+421 age-matched controls) Age $\bar{x}$=30.3±7.6 M:96% Comorbid PTSD 87%	Electronic Medical Records of patient in the VA Integrated Service Network (users of primary care)	• Audiologist • Mental health provider • Neurologist • Neuropsychologist	Average follow-up: $\bar{x}$=1.93±1.1 years PPCS use significantly more services than controls, particularly for: • General medical visits (2.5 times more)	n/s

[27] Janak et al.[143] (2017) Completion of multidisciplinary treatment for persistent postconcussive symptoms is associated with reduced symptom burden

[28] King et al.[144] (2014) Health service and medication use among veterans with persistent postconcussive symptoms

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
				Comorbid chronic pain 76%		• Neurosurgeon • Pain specialist • Primary care mental health provider • Primary care provider • Rehabilitation specialist	• Mental health services (3 times more) PPCS + PTSD + chronic pain used more services that PPCS + PTSD Mean PPCS treatment $\bar{x}$=2 years	
29	United States	Cohort study	General	At follow-up: • 231 ○ 173 head injury only (inc. 13 with extreme persistent PCS) ○ 58 head injury with PTA or LoC (inc. 1 with extreme persistent PCS)	Emergency Department	n/s	• Outliers on the Rivermead Post-concussion questionnaire at 12 months were also outliers at emergency department. • Outliers showed increased use of healthcare services compared to non-outliers between 3 and 12 months postinjury.	n/s
30	United States	Cohort study	General	689 mTBI + 1319 controls	Emergency department	• Chiropractor • Occupational therapist • Physical therapist • Physician • Psychologist	• Use of healthcare services post ED-discharge more frequent in patient in mTBI • At 6 months, 42% of the mTBI cohort that were using physicians' services at 3 months were still using that service	n/s
31	United States	Cohort study	General	120 TBI: • 60 with Hx of depression treatment	Medical charts	• Midlevel provider • Neuropsychologist • Occupational therapist	• Patient with no history of pre-TBI depression treatment use more services than patient with history of pre-TBI depression treatment.	n/s

[29] Kirsch et al.[145] (2010) Characteristics of a mild head injury subgroup with extreme, persisting distress on the Rivermead postconcussion symptoms questionnaire

[30] Kraus et al.[146] (2014) Sustained outcomes following mild traumatic brain injury: results of a five-emergency department longitudinal study

[31] Kruse et al.[147] (2018) Pharmacologic treatment for depression at injury is associated with fewer clinician visits for persistent symptoms after mild traumatic brain injury: a medical record review study

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
				• 60 without Hx of depression treatment		• Physical therapist • Physician • Psychologist		
32	United States	Cohort study	Military	62 seen in clinic (of 166 referred)	Polytrauma Network System Palo Alto	• Neuropsychologist • Occupational therapist • Optometrist • Physiatrist • Physical therapist • Speech and Language Pathologist • Social worker	Patients referred to clinic if positive TBI screen	n/s

33	United States	Cohort study	General	24	Neuropsychology clinic	• Neuropsychologist	• 8/24 Sx-free at 2 weeks, return to normal daily activities at 2 months
							• 16/24 with significant Sx at 2 weeks
							  ○ 11/16 good recovery at 2 months
							  ○ 5/16 still impaired at 8 weeks and referred to neuropsychology services
							  ▪ 4 referred for comprehensive assessment and subsequent 13w individual outpatient cognitive and psychological therapy
								n/s

34	United States	Cohort study	General	32 usual care and 32 early intervention	Emergency Department	• Emergency department medical staff	• Increased medical services use at 3 months post-injury in both groups, but no increase in psychiatric service use. No significant difference between groups. • Change in medical accessed posited to be due to complications of mTBI and/or comorbid injuries	n/s
35	United States	Cohort study	General	73 (M:52; F:21)	Georgia Model Brain Injury System Rehabilitation hospital	• Occupational therapist • Physical therapist • Physician • Psychological counsellor	• Likelihood of service use was not a factor of injury severity, but intensity of use was	n/s

[32] Lew et al.[148] (2007) Program development and defining characteristics of returning military in a VA polytrauma network site

[33] Mateer[118] (1992) Systems of care for post-concussive syndrome

[34] Moore et al.[149] (2014) The emergency department social work intervention for mild traumatic brain injury (swift-acute): a pilot study

[35] Phillips et al.[150] (2004) Severity of injury and service utilization following traumatic brain injury: the first 3 months

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
						• Recreational therapist • Speech and language therapist • Vocational therapist		
36	United Kingdom	Cohort study	General	33 contacted, 20 seen in clinic	Emergency Department	• Accidents and emergency consultant • Consultant neurosurgeon • General practitioner • Head injury specialist nurse • Neuropsychiatrist • Neuropsychologist • Vision specialist	• Description of nurse-led clinic, where nurse acts as care coordinator. • Care is multidisciplinary. 33 patients followed up by nurse specialist: • 11 had no PCS and required no further follow-up (although retained option to contact nurse of symptoms emerge). • 6 received written information leaflet about mTBI and were offered a further phone follow-up • 14 received a nurse referral • Trajectories of 2 patients not accounted for in study 20 were offered a clinic appointment (included 6 referral directly from the neurosurgeon in hospital). Those see in clinic received either a further clinic appointment, phone follow-up or were discharged with the opportunity to come back to the clinic if required.	90
37	United States	Cohort study	Military	TBI 127 M: 126; F:1 Age: [<25]: 77 [25-29]: 29 [≥30]: 21 And Non-TBI 419 M: 409; F: 10 Age: [<25]: 228	Expeditionary Medical Encounter Database Career History Archival Medical Personnel System	• Occupational therapist • Physical therapist • Prosthetist	• In 49% of TBI sample, Dx of TBI was not made on the same day as other injuries • 89% TBIs Dxed by 30d postinjury • Patients with TBI have higher number of medical and rehabilitation out and in-patient visits (physio, OT, and prosthetics consults. Particularly high for OT for much of the FU period.	n/s

[36] Powell[151] (2005) Improving follow-up for head injury patients in a nurse-led post-concussion clinic

[37] Rauh et al.[152] (2013) Effect of traumatic brain injury among US servicemembers with amputation

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
				[25-29]: 103 [≥30]: 88				
38	Australia	Cohort study	General	20 M:10; F: 10 Age $\bar{x}$=31.2±11.4; [18,52]	Specialist rehabilitation centre	• General medical practitioner • Neurologist	• Patients referred to clinic by neurologists or GPs • Mean duration of PCS in sample $\bar{x}$=3.35 • Sample of patients with persisting PCS represents around 20% of all referrals to rehab centre. • Sx presented in clusters with ebb and flow phases	180
39	United Kingdom	Cohort study	General	1235 M: 73% Age median 32, [1,90]	Specialist neurotrauma clinic – neurotrauma database	• Clinical psychologist • General practitioner • Multidisciplinary team • Neurorehabilitation consultant • Neurosurgeon • Occupation therapist • Psychology assistant • Speech and language therapist	• Main referral sources: ○ Neurosurgery ○ GPs ○ clinical decision unit • Peak time post injury to referral is 3 months, but numbers are still high up to 12 months. • Referral source are different based on time since injury: ○ Earlier ones from A&E ○ Peak between 3 and 12 months for neurosurgery ○ Later stages: increasing referrals form GPs and other specialities • 1/3 of referrals initially classified as mild. • 11% had not been admitted. • Of the patients that needed extended follow up: 31% had mild injury • Of those requiring specialist community rehabilitation, 29% had mild head injury	n/s
40	Australia	Cohort study	General	175 Male: 68% Age at injury $\bar{x}$=37.0±15.1, [16,87] median=34.8	Tasmanian Neurotrauma Register Community rehabilitation unit	• Allied healthcare professionals • Clinical psychologist • Medical professionals • Neuropsychologist • Nurse • Occupational therapist • Physiotherapist	• Majority mild TBI • 63% referred within first 3 months • 30% between 3 and 12 months Referral destinations varied depending on referral sources: • Research assistants → Nursing, psychology • Medical / allied HCPs → Physio, OT, psychology Rehabilitation is multidisciplinary: • 33% referred to 2 disciplines • 25% to 3 disciplines Worse PCS associated with more frequent referrals to:	90

[38] Rees & Bellon[153] (2007) Post concussion syndrome ebb and flow: longitudinal effects and management

[39] Seeley et al.[91] (2014) The epidemiology of a specialist neurorehabilitation clinic: implications for clinical practice and regional service development.

[40] Ta'eed et al.[154] (2015) Service utilisation in a public post-acute rehabilitation unit following traumatic brain injury

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
						• Research assistant • Social worker	• Nursing • Psychology • Social work	
41	Australia	Cohort study	General	1226 M:65% Age $\bar{x}$=36.9±17.81; [16,97]	Tasmanian Neurotrauma Register	• Allied health care professionals • Medical professionals • Research assistant	• 804 received no rehabilitation (of which 84% had mild TBI • 175 were referred to community rehabilitation unit • 54 from medical and allied HCPs, 24% with mTBI • 121 from research assistants, 65% with mTBI) • 63% referred within 3 months post-injury (with majority of these referred from medical and Allied HCPs) • 247 went to private rehabilitation services (60% with mTBI)	n/s
42	New Zealand	Cohort study	General	147 M: 42% Age $\bar{x}$=33.1±17.6	Concussion clinic	• Key worker • Multidisciplinary team • Neuropsychologist • Occupational therapist • Physician • Physiotherapist • Rehabilitation physician	Injury to assessment time: $\bar{x}$=46.2±15.8 days Concussion service: • Key worker (OT here) performs initial triage • MDT case review • Physio assessment and other assessments as indicated • Individualised treatment recommendations • Further individualised treatment is provided outside of service. Neck and vestibule-ocular physiotherapy is very commonly recommended for patients with PCS	14
43	United States	Cohort study	General	1272 physiotherapists 70% trained in concussion management	American Physical Therapy Association	• Neurologist • Physician • Physiotherapist • Primary care provider	Referral sources: • Primary care practitioners • Neurologists Referral destinations: • Other physio specialties • Physician • Discharge with no further referral	14
44	United States	Consensus conference	Military	50 subject matter experts (healthcare professionals,	n/s	• Case manager • Family practitioner • Mental health provider	Specifically looking at pathway for chronic PCS (≥ 3months post-injury) <u>Screening:</u> • Cog Sx+ and (TBI+ or TBI-) → education + reassurance	90

[41] Ta'eed et al.[155] (2013) Which factors determine who is referred for community rehabilitation following traumatic brain injury?

[42] Van der Walt et al.[156] (2018) How often is neck and vestibulo-ocular physiotherapy treatment recommended in people with persistent post-concussion symptoms? A retrospective analysis

[43] Yorke et al.[157] (2016) Concussion attitudes and beliefs, knowledge, and clinical practice: survey of physical therapists

[44] Helmick[158] (2010) Cognitive rehabilitation for military personnel with mild traumatic brain injury and chronic post-concussional disorder: results of April 2009 consensus conference.

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
				researchers, military representatives)		• Multidisciplinary team • Neuropsychologist • Neurologist • Nurse • Nurse practitioner • Occupational therapist • Patient • Physician • Primary care physician • Psychiatrist • Speech and language therapist • Unit chain of command (military)	• Cog Sx+ and TBI- → back to primary care physician for evaluation of medical/mental health condition • Comorbidities render screening impossible → refer to specialty clinic and assign case manager → repeat cog evaluation in 4w and monthly follow up for 6m • Cog Sx+ and TBI+ → comprehensive assessment indicated <u>Comprehensive assessment</u> • Comprehensive neurological examination ○ No confounding finding → continue ○ Confounding findings → back to primary care physician or refer to specialty clinic • Comprehensive cognitive assessment • Multidisciplinary, neurobehavioural + cognitive evaluations, appoint a team leader/case manager ○ Patient required a full cognitive rehabilitation programme → holistic but tailored to meet needs / treatment offered within discrete therapy model ○ Patient required limited programme → goal setting + education on cognitive and emotional skills to build resilience / short return to duty training to boost confidence	
45	United States	Cross-sectional	General	572 physicians	American College of Sports Medicine	• Family physician • General practitioner • Headache specialist • Internist • Multidisciplinary team • Neurologist • Neuropsychologist • Neurosurgeon • Physiatrist • Psychologist	• Presence of multidisciplinary clinic within 60 miles only true for 59.6% of respondents. • Referral destinations: neurology, neuropsychology, vestibular rehabilitation, multidisciplinary concussion clinic, headache specialist, psychologist, sport medicine, psychiatry, neurosurgery. • No evidence-based guidelines for the management of PCS	90
46	United States	Cross-sectional study	Military	614 M:95.3%; F:4.7% Age x̄=29.8±8.0	All tiers of VHA polytrauma system, identified through the VHA Patient Care Services database	• Case manager • Medical consultant • Multidisciplinary team	Initial screen • First healthcare visit (where initial TBI screen performed) was primarily primary care.	n/s

[45] Rose et al.[159] (2015) Physicians' management practices and perceived health risks when postconcussion symptoms persist

[46] Belanger et al.[160] (2016) The veterans health administration's traumatic brain injury screen and evaluation: practice patterns

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
						• Neurologist • Neuropsychologist • Nurse • Occupational therapist • Orthotist • Physiatrist • Physiotherapist • Recreation therapist • Rehabilitation medicine physician • Rehabilitation specialist • Rehabilitation psychologist • Social worker • Speech pathologist • TBI physician expert • Vocational rehabilitation counsellor	• Average time between fist visit and screen: 28.8 days, but most seen within 1 day. • Site of screen was spread across all tiers of the VHA polytrauma system. • Screen was primarily performed by nurses, social workers/case managers, and physicians/dentists. Comprehensive TBI evaluation • On average 44.3 days between screening and Comprehensive TBI Evaluation (performed if initial screen positive). • CTBIE was performed either by MDT or individual HCP. • Of 614 that received CTBIE, 58.6% TBI Specialist referrals for affective Sx: • 470/594 addressed by CTBIE clinician • 272/470 referred • 157/272 ≥ 1 visit • 89/157 received treatment Specialist referrals for Hearing Sx • 273/545 addressed by CTBIE clinician • 225/273 referred • 145/225 ≥ 1 visit • 106/145 received treatment Specialist referrals for Cognitive Sx • 278/586 addressed by CTBIE clinician • 234/278 referred • 164/234 ≥ 1 visit • 92/164 received treatment	
47	United States	Guideline	General	n/a	n/a	• Speech therapist • Occupational therapist • Physiotherapist • Neuropsychologist	Patients with mTBI often referred for rehabilitation, but no specific set of indications for referral.	90
48	United States	Guideline	General	n/a	n/a	• Neurologist • Psychiatrist • Psychologist	• Neuropsychological testing can be useful in management, but not in acute concussion stage • Referral to specialist can be considered for patients with persisting symptoms	10

[47] Barbosa et al.[161] (2012) Evaluation and management of mild traumatic brain injury: an eastern association for the surgery of trauma practice management guideline

[48] BMJ Best Practice[60] (2018) Concussion

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
49	United Kingdom	Guideline	General	n/a	n/a	• Clinical psychologist • Dietitian • Generic assistant • Nurse • Occupational therapist • Physiotherapist • Rehabilitation medicine consultant • Social worker • Speech and language therapist • Technical instructor	G34 Any ABI patient being considered for hospital discharge should not be discharged until the following areas have been assessed by someone familiar with neurological disability, and all identified needs have been documented and met: (A)23,11,22 • presence of common neurological impairments (see above) which should be documented • safety in the patient's proposed discharge environment • need for continuing immediate active rehabilitation and how this will be met • risk to others – especially where children are involved • awareness of the person and their family or carers of the current problems and how to manage them. G35 ABI patient being considered for hospital discharge, or taking self-discharge, and who has not had an assessment by a member of the specialist neurological rehabilitation team, should be notified to that team (A)13,14 and should have: • preferably a fixed outpatient or domiciliary visit appointment with them • or, if this is impractical and problems are judged to be minor: a planned telephone contact from them within seven days. G36 All patients being discharged after a recent ABI, regardless of follow-up arrangements already made, should: (C)13,14 • be given a card with details of the specialist neurological rehabilitation team and how to contact them • be warned of any likely problems they may face and how to manage them – including the fact that problems sometimes only become apparent some weeks or months later • have a family member or friend also informed of the above (with the patient's agreement). G37 For all patients discharged after ABI from an acute hospital, the primary healthcare team (GP) should: (C)50 • be notified before or at the moment of discharge, with details of residual impairments and planned follow-up • be given the details of the responsible neurological rehabilitation service to contact if problems emerge.	n/s

[49] BSRM[5] (2003) Rehabilitation following acquired brain injury: national clinical guidelines

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
							G38 Any patient who seeks contact with the NHS with symptoms following ABI should be offered an appointment with a professional trained in the sequelae of brain injury. (C)43	
50	United States	Guideline	General	n/a	n/a	n/s	"For patients admitted with confusion or lethargy which does not clear after several days, it is appropriate to consider rehabilitation medicine evaluation and possible referral to a rehabilitative facility. If symptoms are less debilitating but persistent, then outpatient follow-up may be indicated."	90
51	United States	Guideline	Athlete	n/a	n/a	• Multidisciplinary team • Neuropsychologist	"athletes with concussion should have medical follow-up" (p.7) At follow up: • If deterioration → neurological imaging • Else if stable/improving then ○ conservative management (cognitive and physical rest + symptom-limited return to activity + symptom management) ▪ If symptoms continue >7/10 days then MDT management + comprehensive neuropsychological evaluation ▪ If symptoms/deficits then rehab plan (cognitive therapy a/o integrated neurorehabilitation programme a/o supervised progressive exercise programmes	10
52	Canada	Guideline	General	n/a	n/a	• Mental health team • Neuropsychologist • Neuropsychologist • Occupational medicine physician • Occupational therapist • Optometrist • Psychiatrist	"1.7. If the patient re-attends an emergency department/urgent care service with symptoms related to the initial injury, the following should be conducted: • Full re-evaluation, including an assessment for ongoing post-traumatic amnesia (PTA) • CT scan, if indicated • Emphasis and encouragement to the patients to attend their family physician for follow-up after discharge.	90

[50] Cushman et al.[162] (2001) Practice management guidelines for the management of mild traumatic brain injury: the east practice management guidelines work group

[51] Harmon et al.[18] (2013) American medical society for sports medicine position statement: concussion in sport

[52] Marshall et al.[163] (2015) Updated clinical practice guidelines for concussion/mild traumatic brain injury and persistent symptoms

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
						• Speech and language pathologist • Vocational rehabilitation counsellor	1.8. Clinicians should assess, monitor and document persisting somatic, cognitive and emotional/behavioural symptoms following mTBI using a standardized assessment scale. 2.2. Persons who complain about somatic, cognitive or behavioural difficulties after mTBI should be assessed and treated symptomatically, even if it has been a prolonged time after injury. 2.9. Individualized telephone or in-person follow-up with education on symptom management and encouragement to resume everyday activities should be provided over the 12 weeks after injury. 4.1. Clinicians should assess, monitor and document persisting somatic, cognitive and emotional/behavioural symptoms following mTBI using a standardized assessment scale. 5.4. Persons with mTBI and complicating health-related or contextual factors should be considered for early referral to a multidisciplinary treatment clinic capable of managing post-concussive symptoms because these factors have been associated with poorer outcomes."	
53	Australia	Guideline	Athlete	n/a	n/a	n/s	• Multimodal clinical assessment needed to identify any confounding causes of post-concussive symptoms. • Treatment should be individualised and target specific factors identified on assessment i.e. symptom-specific. • Mention of addressing symptom clusters (physical, cognitive, emotional) • PCS cases are complex and require experience multidisciplinary teams	14
54	United Kingdom	Guideline	General	n/a	n/a	General practitioner Family Carer Clinical psychologist Neurologist	• "1.9.10 Inform patients and their families and carers about the possibility of persistent or delayed symptoms following head injury and whom to contact if they experience ongoing problems."	n/s

[53] McCrory et al.[164] (2017) Consensus statement on concussion in sport-the 5th international conference on concussion in sport held in berlin, October 2016

[54] NICE[26] (2014) Head injury: assessment and early management

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
						Neurosurgeon Rehabilitation medicine specialist	• "1.9.11 For all patients who have attended the emergency department with a head injury, write to their GP within 48 hours of discharge, giving details of clinical history and examination. This letter should also be shared with health visitors (for pre-school children) and school nurses (for school-age children). If appropriate, provide a copy of the letter for the patient and their family or carer." • "1.9.12 When a patient who has undergone imaging of the head and/or been admitted to hospital experiences persisting problems, ensure that there is an opportunity available for referral from primary care to an outpatient appointment with a professional trained in assessment and management of sequelae of brain injury (for example, clinical psychologist, neurologist, neurosurgeon, specialist in rehabilitation medicine)."	
55	Canada	Guideline	General	n/a	n/a	• Accommodation specialist • Athletic therapist • Audiologist • Chiropractor • Clinical psychologist • Clinical psychologist • Coach • Emergency physician • Family physician • Kinesiologist • Massage therapist • Multidisciplinary team • Neurologist • Neuro-ophthalmologist • Neuropsychologist • Neuropsychologist • Neurosurgeon • Nurse • Nurse practitioner	• Concussion Dx → FU: 1-2weeks • If Sx not improving → regular follow-up assessment with experience HCP → Sx based referrals, unless patient would benefit from multidisciplinary care → MDT + involvement of primary care provider + external referrals if necessary • Research suggests that 15-20% of patient are in the MDT part of the pathway. • Multidisciplinary care should be coordinated and does not need to happen within a single physical setting	14

[55] ONF[165] (2017) Standards for post-concussion care: from diagnosis to the interdisciplinary concussion clinic

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
						• Nutritionist • Occupational therapist • Ophthalmologist • Optometrist • Orthopaedic surgeon • Otolaryngologist • Physician • Physiotherapist • Primary care provider • Social worker • Specialist in headache management • Speech and language pathologist • Sport medicine physician • Sports medicine physician • Vocational rehabilitation worker		

56	Canada	Guideline	General	n/a	n/a	• Chiropractor
						• Clinic coordinator
						• Dietician
						• Emergency physician
						• Family
						• Family physician
						• Kinesiologist
						• Massage therapist
						• Medical doctor
						• Mental health specialist
						• Multidisciplinary team
						• Naturopath
						• Nurse
							If Sx persist beyond 4 weeks:
							• Complicated health-related / contextual factors?
							  ○ Yes → early referral
							  ○ No → Reassess regularly and initiate Sx-based treatment
							• Sx / functional status improved?
							  ○ Yes → Encourage + reinforce + monitor
							  ○ No → Implement supervised return to activity + prioritise pain management
							• Mental health disorder Dx?
							  ○ Yes → manage comorbidity + consider referral to mental health specialist
							• Any persistent Sx?
							  ○ Yes → Refer to appropriate specialist
								30

[56] ONF[166] (2018) Guideline for concussion/mild traumatic brain injury & persistent symptoms

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
						• Nutritionist • Occupational therapist • Orthopaedic surgeon • Physiotherapist • Physiotherapist • Primary care providers • Psychologist • Social worker • Speech and language pathologist • Sport surgeon	○ No → Consider referral to occupational/vocational therapy + encourage and monitor for comorbid conditions + follow-up and reassess in 3-4 months	
57	Canada	Guideline	Athlete	n/a	n/a	• Multidisciplinary team • Neurologist • Neuropsychologist • Neurosurgeon • Nurse practitioner • Occupational therapist • Physiotherapist • Rehabilitation medicine physician • Sport medicine physician	• If persistent Sx → Multidisciplinary concussion care • Referral made on individual basis at discretion of assessing clinician. If MDT clinic not available, refer to clinician with expertise in concussion management • Treatment will be Sx-based	14
58	United Kingdom	Guideline	General	n/a	n/a	• Multidisciplinary team • Vocational counsellor • Speech and language therapist • Physiotherapist • Psychologist • Occupational therapist • Neuropsychologist • Orthotist	• Treatment is largely Sx-based • "3.3.2 Referral for cognitive (psychometric) assessment is not routinely recommended after MTBI." • "3.4.3 Referral for cognitive behavioural therapy following MTBI may be considered in patients with persistent symptoms who fail to respond to reassurance and encouragement from a general practitioner after three months" • "5.8 In the post-acute setting interventions for cognitive deficits should be applied in the context of a comprehensive/holistic neuropsychological	90

[57] Parachute[167] (2017) Canadian guideline on concussion in sport

[58] SIGN[168] (2013) Brain injury rehabilitation in adults: a national clinical guideline

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
						• Pharmacist	rehabilitation programme. This would involve an interdisciplinary team using a goal-focused programme which has the capacity to address cognitive, emotional and behavioural difficulties with the aim of improving functioning in meaningful everyday activities."	
59	United States	Guideline	Military	n/a	n/a	• Case manager • Multidisciplinary team	Recommendations are largely symptom-specific. For more global PCS recommendations: • "4. We recommend against performing comprehensive neuropsychological/ cognitive testing during the first 30 days following mTBI. For patients with symptoms persisting after 30 days, see Recommendation 17." (p.19) • "6. For patients with new symptoms that develop more than 30 days after mTBI, we suggest a focused diagnostic work-up specific to those symptoms only." (p.19) • "8. We suggest considering, and offering as appropriate, a primary care, symptom-driven approach in the evaluation and management of patients with a history of mTBI and persistent symptoms." (p.19) • "17. We suggest that patients with a history of mTBI who report cognitive symptoms that do not resolve within 30-90 days and have been refractory to treatment for associated symptoms (e.g., sleep disturbance, headache) be referred as appropriate for a structured cognitive assessment or neuropsychological assessment to determine functional limitations and guide treatment." (p.21) • "18. We suggest that individuals with a history of mTBI who present with symptoms related to memory, attention or executive function problems that do not resolve within 30-90 days and have been refractory to treatment for associated symptoms should be referred as appropriate to cognitive rehabilitation therapists with expertise in TBI rehabilitation. We suggest considering a short-term trial of cognitive rehabilitation treatment to assess the individual patient responsiveness to strategy training, including instruction and practice on use of	90

[59] US Department of Veterans Affairs & US Department of Defense[10] (2016) VA/DOD clinical practice guideline for management of concussion/mild traumatic brain injury

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
							memory aids, such as cognitive assistive technologies (AT). A prolonged course of therapy in the absence of patient improvement is strongly discouraged." (p.21) • "20. We suggest against routine referral to specialty care in the majority of patients with a history of mTBI." (p.21) • "21. If the patient's symptoms do not resolve within 30-90 days and are refractory to initial treatment in primary care and significantly impact activities of daily living (ADLs), we suggest consultation and collaboration with a locally designated TBI or other applicable specialist." (p.21) • "22. For patients with persistent symptoms that have been refractory to initial psychoeducation and treatment, we suggest referral to case managers within the primary care setting to provide additional psychoeducation, case coordination and support." (p.21) • "23. There is insufficient evidence to recommend for or against the use of interdisciplinary/multidisciplinary teams in the management of patients with chronic symptoms attributed to mTBI." (p.21)	
60	Canada	Randomized Trial	General	97 (MDT intervention) Age $\bar{x}$=30.7±10.9 M:64; F:33 94 (no follow up or treatment offered) Age $\bar{x}$=33.3±12.4 M:60; F34	Emergency department	• Physician	• Control group still accessed healthcare, with $\bar{x}$=1.8±1.5 visits • Specialties consulted or reasons for visits not explored/reported.	n/s
61	Canada	Randomized trial	General	TAU+CBT 15 Male 40% Age $\bar{x}$=40.4±13.5 TAU 13 Male: 38%	Concussion clinic	• Concussion clinic service coordinator • Family physician • Occupational therapist	• Treatment as usual included • Single 3-hour sessions with clinic service coordinator (here an OT) • Opportunity for referral to rehabilitation professionals as needed	90

[60] Ghaffar et al.[169] (2006) Randomized treatment trial in mild traumatic brain injury

[61] Silverber[170] (2012) Cognitive-behavioral prevention of post-concussion syndrome in at-risk patients: a pilot randomized controlled trial

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
				Age $\bar{x}$=37.5±10			• Mean number of days since injury at recruitment: TBI+CBT $\bar{x}$=23.13±7.0; TBI $\bar{x}$=25.4±9.1 • Acknowledgement that treatment as usual in this clinic likely goes beyond the current clinic management of TBI: education material and "vague recommendations to rest" (p.320)	
62	Canada	Randomized trial	General	60 TAU + advice for gradual return to activity M:40% Age $\bar{x}$=34.3±13.4 and 58 TAU M: 32.8% Age $\bar{x}$=36.1±14.2	Emergency department	• Emergency department nurse • Emergency department physician	Discharge instructions include: • warning signs for more serious injury • common symptoms following TBI • recommendations for rest and graduated return to activity (for intervention group only) Visits post injury for mTBI Sx (4 weeks post injury): • Intervention: 34.8% • Control: 43.2% No significant difference in Sx change, missed days of work or school, or healthcare visits post injury between groups	10
63	United Kingdom	Randomized trial	General	1156 M:760; F:396 Age $\bar{x}$=30±13, median 26 • 579: TAU + routine follow-up • 577: TAU	Oxford Head Injury Service register (information fed from Emergency Departments and trauma wards)	n/s	• No routine follow-up in treatment as usual for patients "attending or admitted to hospital after uncomplicated brain injury" (p.479) • No significant difference in symptoms at 6 months between controls and group that received routine follow-up. Argues that it's not necessarily ineffective, it's just that most patients do not need it, and it is key to identify those that might benefit early on	90
64	United States	Review article	General	n/a	n/a	• Case manager • Family • Multidisciplinary team • Social worker	• Care is driven by symptoms presentation as aims of therapy is to "improve identified problems rather than affect a cure". • Structure of assessment of people with PCS is set: o Check for red flags and refer to ED if needed o Check for root cause and treat if identified o Check for comorbidities and treat if identified o Address physical, cognitive and behavioural Sx as required	14

[62] Varner et al.[171] (2017) Cognitive rest and graduated return to usual activities versus usual care for mild traumatic brain injury: a randomized controlled trial of emergency department discharge instructions

[63] Wade et al.[172] (1997) Does routine follow up after head injury help? A randomised controlled trial

[64] Blyth & Bazarian[173] (2010) Traumatic alterations in consciousness: traumatic brain injury

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
							○ If Sx are being treated, follow-up should occur 4 to 6 weeks following therapy initiation • PCS is considered persistent if patient is refractory to treatment, in which case refer to appropriate specialists, and set up regular follow ups • Care typically multidisciplinary, case worker is key	
65	United States	Review paper	Athlete	n/a	n/a	• Athletic trainer • Coach • Concussion specialist • Multidisciplinary team • Neurologist • Parent • Physiatrist • Physician • Sideline medical team • Teacher	• PCS (Sx lasting 5-10d) should be managed through rest • Prolonged PCS (Sx lasting >6m) should be managed through a combination of rest, vestibular rehabilitation and reassessment.	10
66	New Zealand	Review paper	General	n/a	n/a	• Ophthalmologist • Otolaryngologist • Orthoptist • Carer • Employer • Neurologist • Occupational therapist • Physiotherapist • Psychologist • Psychiatrist • Head injury rehabilitation practitioner	• PCS (Sx lasting >2-3w) should prompt referral to specialists, but more Sx-specific • Persistent PCS (lasting 3-6m), still mostly Sx-driven, but element of biopsychosocial assessment and some suggestion of MDT involvement.	21
67	United States	Review paper	Military	n/a	n/a	• Concussion specialist • Rehabilitation specialists	• Screening for Hx of TBI is systematic in the VA HC system and includes a criteria point about presence of PCSx.	n/s

[65] Aligene & Lin[174] (2013) Vestibular and balance treatment of the concussed athlete

[66] Anderson et al.[175] (2006) Concussion and mild head injury

[67] Armistead-Jehle et al.[176] (2017) Unique aspects of traumatic brain injury in military and veteran populations

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
						• Primary care providers • TBI specialist	• Patients screening positive are referred to TBI specialist for comprehensive evaluation. • Positive FU lead to development of care plan using the four-tiered Polytrauma System of Care and includes social care involvement through the Integrated Disability Evaluation System. • Where TBI is recognized in combat theatre, rehabilitation can start at MTFs onsite before transfer to rehab facilities stateside	
68	United States	Review paper	Military	n/a	n/a	• Case manager • Medical consultant • Multidisciplinary team • Neurologist • Neuropsychologist • Nurse • Occupational therapist • Orthotist • Physiatrist • Physiotherapist • Recreation therapist • Rehabilitation medicine physician • Rehabilitation specialist • Rehabilitation psychologist • Social worker • Speech pathologist • TBI physician expert • Vocational rehabilitation counsellor	• Structure of VHA Polytrauma System of Care described • 4 tiers covering acute and community settings, and both in and out-patient services • All patients within the PSC receive ongoing case management by nurses and social workers • Support offered to both patients and families	30
69	United States	Review paper	General	n/a	n/a	• Multidisciplinary team • Neurologist	• MDT, case management • Treatment is symptom-driven. • Rehabilitation clinic setting	

[68] Belanger et al.[177] (2009) The veterans health administration system of care for mild traumatic brain injury: costs, benefits, and controversies

[69] Boake et al.[178] (1991) Rehabilitation of the patient with mild traumatic brain injury

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
						• Neuropsychologist • Neurosurgeon • Ophthalmologist • Otolaryngologist • Physiatrist • Physiotherapist • Psychiatrist • Psychotherapist • Radiologist • Rehabilitation nurse • Speech and language therapist		
70	United States	Review paper	General and athlete	n/a	n/a	• Behavioural health specialist • Clinical neuropsychologist • Cognitive therapy • Multidisciplinary team • Physiotherapist • Visual therapist	• MDT • Management is Sx-based	10
71	United States	Review paper	General	n/a	n/a	• Adjustor • Attorney • Chiropractor • Employer • Family practitioner • Forensic medical expert • Insurance case manager • Internist • Multidisciplinary team • Neurologist • Neuropsychologist • Neurosurgeon	• Multidisciplinary team with an oversight of overall management (case manager). • Management is Sx-based. • Assessment divided into physical and cognitive/emotional	90

[70] Bramley et al.[179] (2016) Mild traumatic brain injury and post-concussion syndrome

[71] Chang et al.[180] (2011) Mild traumatic brain injury in the occupational setting

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
						• Occupational medicine physician • Occupational therapist • Otolaryngologist • Physiatrist • Physiotherapist • Speech and language therapist • Vestibular therapist		
72	United States	Review paper	Athlete	n/a	n/a	• Athletic trainer • Multidisciplinary team • Neuro-optometrist • Neuropsychologist • Neuro-radiologist • Orthopaedic surgeon • Primary care physician • Primary care sport physician • Psychotherapist • Speech and language therapist • Vestibular therapist • Vision therapy specialist	• Sx are grouped in clusters but not confined to any single cluster. • Management is more holistic and following the "trajectory" the patient is on. • Assessment initially in first seven days and secondary assessment after that period to identify Sx trajectory • Management is multidisciplinary with case manager (neuropsychologist)	21
73	Canada	Review paper	Athlete	n/a	n/a	• Cervical spine physiotherapist • Exercise physiologist • Headache neurologist • Kinesiologist • Multidisciplinary team • Neurologist	• PCS presents in different subtypes/clusters: physiological, vestibule-ocular, cervicogenic. • Management approaches are individualised based on these presentations. • Multidisciplinary teams are involved • Decision to give medical clearance is also multidisciplinary.	14

[72] Collins et al.[64] (2014) A comprehensive, targeted approach to the clinical care of athletes following sport-related concussion

[73] Ellis et al.[181] (2016) Multi-disciplinary management of athletes with post-concussion syndrome: an evolving pathophysiological approach

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
						• Neuro-ophthalmologist • Neuropsychologist • Neurosurgeon • Psychiatrist • Sport medicine physician • Vestibular physiotherapist		
74	Canada	Review paper	Athlete	n/a	n/a	• Athletic therapist • Athletic therapist • Cervical spine physiotherapist • Chiropractor • Exercise physiologist • Multidisciplinary team • Neuro-ophthalmologist • Neuro-optometrist • Neurosurgeon • Physiotherapist • Rehabilitation medicine physician • Sport medicine physician • Sport neurologist • Vestibular physiotherapist	• Built upon 2016 paper, with added consideration that initial medical investigations must identify pathophysiological causes to inform rehabilitation strategies. • Management is blanket for initial post-injury period and largely conservative. Individualized rehabilitation only starts if symptoms persist (>2 weeks post-injury). • MDT involvement, esp. for medical clearance. • No clear consensus on what "recovered" means.	14

75	United Kingdom	Review paper	General	n/a	n/a	• General practitioner
						• Neuropsychologist
							• Follow up for patients with TBI is inconsistent
							• Routine follow-up is rarely offered
							• Advice to return to hospital or GP if further treatment is required.
							  ○ Symptoms present at 1w → do not return to work
							  ○ Symptoms present at 1 month → seek help through head injury rehab units, neuropsychologist, charitable sector
								30

[74] Ellis et al.[182] (2018) A physiological approach to assessment and rehabilitation of acute concussion in collegiate and professional athletes

[75] Hutchinson et al.[183] (1998) The management of minor traumatic brain injury

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
76	United States	Review paper	General	n/a	n/a	• Multidisciplinary team • Physiotherapist • Occupational therapist • Speech and language therapist • Physician	• Treatment should be symptom-based and involve a multidisciplinary team • Patient with prolonged recovery may benefit from "comprehensive concussion programme" (p.9)	n/s
77	United States	Review paper	Military	n/a	n/a	• Family • Multidisciplinary team • Neurologist • Neurosurgeon • Ophthalmologist • Optometrist • Otolaryngologist • Psychiatrist • Psychologist • Social worker	• "Systematic follow up of [symptomatic] patients with mTBI is imperative for clinicians to ensure adequate resource delivery and recovery" (p.660) • Cornerstones of TBI Sx (cognitive deficits, difficulty concentrating, language comprehension difficulties and impaired judgement) make it difficult for patient group to navigate complex system of care. • Pivotal role for care coordination in referring patients to services overtime.	n/s
78	United States	Review paper	Athlete	n/a	n/a	• Neuropsychologist • Psychiatrist	Management is conservative, then symptoms treated in isolation "as there are no large, randomized trials to guide therapy, treatment must be individualised and Sx treated as they would be in an uninjured patient" (p.25)	42
79	United States	Review paper	Mixed: Athlete and military	n/a	n/a	• Neurologist • Neuropsychologist • Occupational therapist • Physiotherapist • Psychiatrist • Psychologist • Speech and language therapist	• If TBI does not resolve within 10-14 days, escalate to TBI medical unit • If Sx severe → medical evacuation out of theatre → acute care unit at military treatment facility with multidisciplinary assessment → acute inpatient rehab → (if not fully recovered) transitional rehabilitation programmes (in- or outpatient) • Cognitive behavioural therapy approach for holistic treatment, but otherwise suggests that treatment is symptom-driven	14

[76] Jackson & Starling[184] (2018) Concussion evaluation and management

[77] Jaffee et al.[185] (2009) Acute clinical care and care coordination for traumatic brain injury within department of defense

[78] Jotwani & Harmon[186] (2010) Postconcussion syndrome in athletes

[79] Kelly et al.[187] (2012) Mild traumatic brain injury: lessons learned from clinical, sports, and combat concussions

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
80	United States	Review paper	Military	n/a	n/a	• Multidisciplinary team • Neuropsychologist • Neurologist • Psychiatrist • Primary care physician	• PCS often treated in primary care (because largely focused on watchful rest and pain management. • A large proportion are referred for behavioural interventions (psychoeducation, sleep hygiene education, relaxation skills, cognitive restructuring and symptom tracking) • Neuropsychological referrals can help clarify diagnosis, quantify deficits and guide treatment • Course of action is then Sx-driven. Because of potentially complex symptom clusters, need for integrated primary care team	90
81	United Kingdom	Review paper	General	n/a	n/a	• General practitioner • Multidisciplinary team	• PCS lasting 4-6 weeks should prompt self-referral to GP • Management is supportive and symptom-driven. • Management can occur through multidisciplinary neurotrauma clinics and support can be found via patient groups	42
82	United States	Review paper	Athlete	n/a	n/a	• Athletic trainer • Multidisciplinary team • Neurologist • Neuropsychologist • Physiatrist • Physical therapist • Primary care physician • Psychiatrist	• In cases of protracted recovery, treatment should be Sx-driven, but multidisciplinary teams can be involved in addressing overlapping Sx of Sx clusters • PCS has a long list of differentials so when suspected, the medical workup must be thorough in an attempt of identify sources other than the concussion	180
83	United States	Review paper	General	n/a	n/a	• Neuropsychologist	Patients with PCS at 6 weeks should receive neuropsychological evaluation, although that is often pushed to 12 weeks in practice	42
84	United States	Review paper	Military	n/a	n/a	• Audiologist • Kinesiotherapist • Medical provider	• Care is largely symptom-driven, which can lead to silos of care	n/s

[80] King & Wray[188] (2012) Managing behavioral health needs of veterans with traumatic brain injury (TBI) in primary care

[81] Kolias et al.[189] (2013) Traumatic brain injury in adults

[82] Laker[190] (2015) Sports-related concussion

[83] Matz[191] (2003) Classification, diagnosis, and management of mild traumatic brain injury: a major problem presenting in a minor way

[84] Merritt et al.[192] (2019) Neurobehavioral management of the polytrauma veteran

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
						• Mental health provider • Multidisciplinary team • Neurologist • Neuroophthalmologist • Neuropsychologist • Neuropsychologist • Occupational therapist • Optometrist • Orthopaedist • Physiotherapist • Psychiatrist • Psychologist • Psychotherapist • Recreation therapist • Rehabilitation medicine physician • Rehabilitation provider • Speech and language therapist • Vision rehabilitation specialist • Vocational rehabilitation specialist	• Care is multidisciplinary for these patients with complex needs, but having oversight in the form of a case manager is key.	
85	United States	Review paper	Military	n/a	n/a	n/s	• Mild TBI in combat theatre is managed in primary care on site. • If Sx not resolved after 2 weeks, patient evacuated (through Landstuhl if stabilisation needed) stateside. • Post deployment evaluation leading to comprehensive TBI evaluation if symptomatic.	n/s

[85] Meyer et al.[193] (2010) Combat-related traumatic brain injury and its implications to military healthcare

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
86	United States	Review paper	Military	n/a	n/a	n/s	Reviewed the resource utilization over time of military patients/veterans with mTBI: 7 low quality studies identified looking at resource use. • Few differences between mTBI and similar controls. • No significant association or risk factors identified	n/s
87	United States	Review paper	Military	n/a	n/a	• Clinical educator • Clinical psychologist • Physical therapist • Recreational therapist • Rehabilitation physician • Social worker • Speech and language pathologist • Vocational rehabilitation therapist	• Little is known about impact of mTBI on healthcare resource use: some suggest there is no distinct impact other say mTBI vastly increases healthcare costs. Highlight that there is a real gap in knowledge regarding pathways of care for active duty service members and veterans. • Rehabilitation programmes should focus on community reintegration	n/s
88	United States	Review paper	General	n/a	n/a	• Emergency department staff • Neuropsychologist • Primary care physician	• Guidelines for acute care are inconsistent (ref 9) • High proportions of patient with mTBI go undiagnosed. Problematic because they are then risk of complicated recovery. • Majority of patient with mTBI do not received follow-up care • Need for clearer guidelines regarding discharge instructions and psychoeducation for all patient (includes all mTBI discharged at emergency department level). • Need for research about targets and timeliness of follow-up care • If high risk, patients should receive early referral to neuropsychology. • If not high risk but persisting symptoms beyond period of typical recovery, patients should receive referral to neuropsychology.	n/s

[86] O'Neil et al.[194] (2013) Complications of mild traumatic brain injury in veterans and military personnel: a systematic review

[87] Pogoda et al.[195] (2017) Health services and rehabilitation for active duty service members and veterans with mild TBI

[88] Prince[196] (2017) Evaluation and treatment of mild traumatic brain injury: the role of neuropsychology

ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
89	United States	Review paper	Athlete	n/a	n/a	• Care coordinator • Multidisciplinary team • Team physician	• No clear guidelines about how to deal with PCS. Vagueness is characteristic of other TBI care guidelines. • "The Team Physicians Consensus Conference does not provide specific recommendations regarding the treatment of complex cases or mention the need for consultation" (p.568) • Care coordination is pivotal → TCCP: "[the team physician should] coordinate assessment and treatment for complications" (p.568) • Multidisciplinary team recommended for people with persisting symptoms • Current stance is that "foundation of PCS management is time" (American Medical Society for Sports Medicine) (p.568)	10
90	Canada	Review paper	General	n/a	n/a	• Case worker • Multidisciplinary team • Occupational therapist • Physiotherapist • Psychotherapist • Vocational counsellor	• Lack of evidence-based clinic guidelines • PCS becomes more difficult to treat with time, as psychosocial factors complicate the clinic picture • Development of continuum of care model for TBI that is evidence based and identifies typical recovery patterns. Aim is to augment clinical practice guidelines and clinic judgement: ○ Physical/medical management should occur immediately from injury onset, alongside address of psychological trauma through stress management and counselling. ○ Education about TBI should occur within the first month following injury. ○ Follow-up and assessment of any PCs should occur between 2 and 8 weeks post injury and can prompt single or interdisciplinary treatment. Neuropsychological assessment at 12 weeks to inform further treatment. ○ Work reintegration should be ongoing throughout.	90
91	United States	Review paper	Military	n/a	n/a	n/s	• Current approach to PCS management: ○ Symptoms lasting >4weeks require further management	30

[89] Putukian & Kutcher[197] (2014) Current concepts in the treatment of sports concussions

[90] Rose[198] (2005) Continuum of care model for managing mild traumatic brain injury in a workers' compensation context: a description of the model and its development

[91] Walker et al.[199] (2010) The "postdeployment multi-symptom disorder": an emerging syndrome in need of a new treatment paradigm

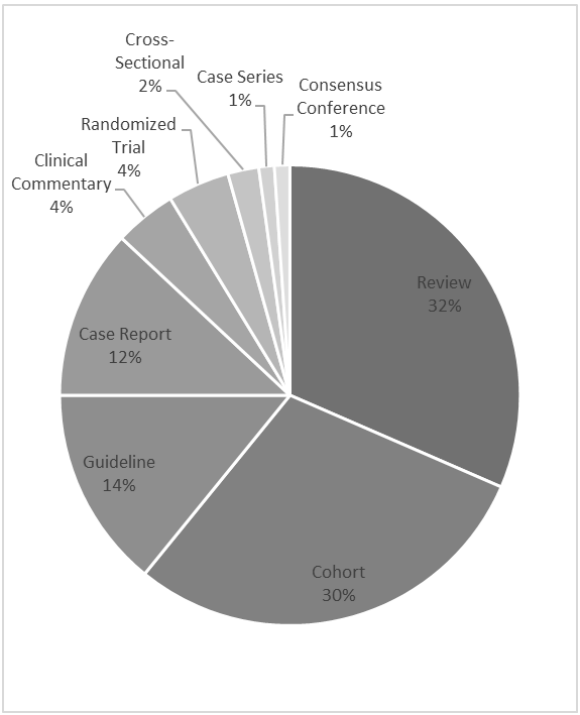
ID	Country	Paper type	Population of interest	Sample details (patients, unless otherwise specified)	Recruitment site	Stakeholders	Findings about care pathways/journeys	Typical recovery (days)
							○ Stepped model of care based on severity and duration of PCS ○ Current approach is Sx-driven • Post-Deployment Evaluation centre allows for care coordination including core and focus treatment focusing on functional recovery, with opportunities for specialist referrals including TBI-specific rehabilitation care. Follow-up at 3, 6, and 12 months and until no more treatment needs are identified, after which patients are discharged with referral to primary care • Referral to PMD from VA/DoD	
92	United States	Review paper	Athlete	n/a	n/a	• Neurologist • Neuropsychologist • Neurosurgeon • Primary care physician • Team physician	Complex concussion at physician visit → consider referral for neuropsychological evaluation → typically multidisciplinary management	21

[92] Willer & Leddy[200] (2006) Management of concussion and post-concussion syndrome

SUMMARY OF MAIN FINDINGS

The papers were categorised based on publication type (Figure 3.4A). They can be broadly divided into primary and secondary sources of evidence. The primary source group was made up mostly of cohort studies (N=27) and case reports (N=11). The secondary source included reviews (N=29) and guidelines (N=13). A majority of the papers was published in the 2010s (Figure 3.4B). Countries of origin based on institutional affiliation of first author showed that papers overwhelmingly came from the United States (N=61), followed by Canada (N=11) and the United Kingdom (N=10). The remaining 9 were from Australia (N=5), New Zealand (N=2), Italy (N=2) and Denmark (N=1).

(A)



*one paper ([118]) was counted both as a cohort study and case reports as both sections were included in the analysis

(B)

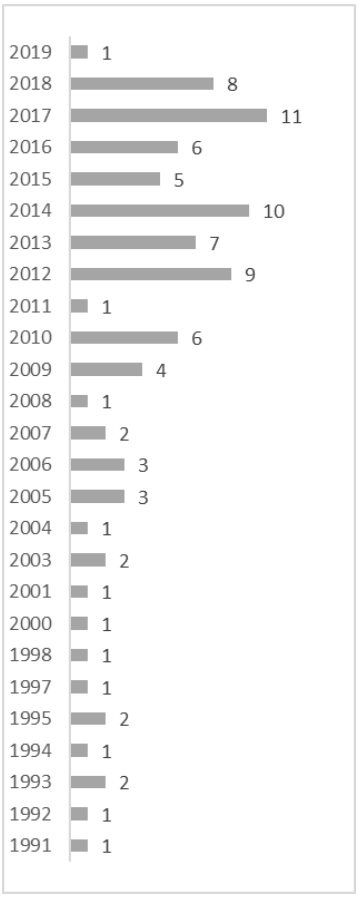


Figure 3.4. Included papers by (A) type and (B) year of publication

SUMMARY OF SEARCH FINDINGS RELATING TO TBI CARE PATHWAYS

Guidelines

We identified 13 guidelines, with only one specific to P-TBI-S management [165]. Most other guidelines discuss P-TBI-S management in the broader context of concussion/mild TBI (mTBI) assessment and management [10,18,164-167]. Four of the guidelines focused primarily on acute management and only mentioned P-TBI-S management very briefly [60,161,162] if explicitly at all [26]. Two of the guidelines dealt with Acquired Brain Injury more generally and mentions of persistent symptoms was not explicitly concerning P-TBI-S [5,168].

Systematic follow-up of patients with mTBI does not appear to be mandated, unless the patient is an athlete, for whom clearance to return to play must be granted by a medical team [18]. Primary care providers should however be notified, and contact details for brain injury specialists should be offered to the patients alongside information about TBI [5,26]. First line of treatment for mTBI is typically watchful cognitive and physical rest followed by gradual return to activity. If symptoms persist beyond the typical recovery timeframe, causes other than the initial brain injury should be ruled out before P-TBI-S is considered [164]. Management of P-TBI-S is largely symptom-driven [10,18,164-166,168]. Specialist assessment should be offered if symptoms are lasting and refractory to initial treatment, or if the patient was suspected to have a more serious injury in acute care (i.e. underwent imaging and/or was admitted to hospital) [5,10,26,162]. Neuropsychological testing may be considered to further define needs if symptoms persist following the initial treatment approach [10,60]. Neuropsychological testing is not recommended in the acute stages of injury [10,60]. Multidisciplinary management options should be explored in patients with complex presentations or aggravating health-related or social factors [18,163,165,166,168], although evidence is limited [10].

Consensus Conference

Results from one consensus conference about P-TBI-S care in military populations were included [158]. Screening for P-TBI-S should lead to comprehensive assessment when both cognitive symptoms are present and a history of TBI is confirmed. Presence of cognitive symptoms alone should be addressed in primary care or prompt referral to other specialists to explore other causes. Any identified co-morbidities should be addressed as a priority and warrant the appointment of a case manager. The comprehensive evaluation should be multidisciplinary and provide a basis for the development of holistic and individually tailored rehabilitation plan.

Reviews

Twenty-nine reviews were included, only 12 of which were not specific to either athlete or military populations. There is a lack of guidelines about P-TBI-S care [197,198], and the evidence about healthcare resource use for these patients is limited [194,195].

First line management for symptoms following TBI is typically rest [174,182,186,188,197,199]. Patients should seek further help when symptoms persist [173,185], although they often have to do so themselves as follow-up is inconsistent and rarely offered [183,189,196]. Beyond rest, care is generally symptom-driven [173,175,178-180,184,186,188-190,192,199].

Neuropsychological testing can be used for patients with persisting symptoms not attributable to other conditions [190]. These assessments can help to further characterise deficits [191,196], notably grouping them into symptom clusters [64,181,188,190]. Earlier neuropsychological testing can also be considered for patients who are at high risk of developing P-TBI-S [196] or have more complex presentations early on [200]. A multidisciplinary approach is preferred to address these persisting symptoms [64,173,175,178-182,184,189,190,192,197,200], although treatment should remained individualised [181,182,186] and a case worker is critical to ensure good care coordination [64,173,177,178,180,185,188,192,197]. Multidisciplinary P-TBI-S care is still largely symptom-centric, although there is some support for more holistic approaches centred on community reintegration [64,184,195,198]

Follow-up in the military context seems more systematic than in other groups of the populations. Notably, the Veterans Affairs Polytrauma System of Care includes systematic TBI screening with automatic referral for comprehensive evaluations [176,177,193].

Cohort, cross-sectional and case series papers

Twenty-seven cohort studies were included. Twenty-one focused on general populations [91,118,133,134,136-140,142,145-147,149-151,153-157] and 6 on military populations [135,141,143,144,148,152]. One case series paper of 435 patients at a rehabilitation hospital [129] and two cross-sectional studies [159,160] were also included here. Four studies were surveys of healthcare professionals [138,140,157,159]. Studies involving patients recruited them in emergency departments [133,145,146,149,151], acute in-patient settings [137], rehabilitation hospitals or specialist clinics [91,118,129,134,136,142,143,148,150,153,156], or through medical charts and databases [139,141,144,147,152,154,155,160]. One of the studies on military cohorts recruited participants in a post-deployment clinic [135].

Two studies reported average clinic stay between 6 and 14 weeks [134,143]. However, P-TBI-S care may take years [144] as the average time between injury and assessment in multidisciplinary/specialist clinic varied, ranging from 6 weeks to well over a year [91,129,136,143,155,156,160].

Nine studies explored changes in service use. Overall, patients with mTBI showed an increase in access to services [144,146,147,149,152]. Some studies suggested that injury, P-TBI-S severity or level of comorbidity may be a factor of intensity of use, but not necessarily of likelihood of access [142,144,145,150,152]. One study showed services used by people with mTBI were not significantly different from those used by controls with non-TBI minor injuries, with the exception of neurology services[141]. One study showed that service use was also elevated prior to injury in patients with mTBI compared to controls [139], another found prompted follow-up rate at 1 month to be similar between mTBI patients and orthopaedic controls [133].

Care for P-TBI-S is multidisciplinary and relies on good care coordination [143,151,155,156]. Multidisciplinary clinics have multiple referral sources, including emergency departments [91,134,151], clinical decision units [153], neuro/general/trauma surgeons [91,134], neurologists [153,157], specialist nurses [136], primary care physicians [91,134,143,148,153,157], as well as attorneys [136] or research staff [155]. Referral destinations after discharge from multidisciplinary clinics include psychology/neuropsychology/neuropsychiatry[134], specialist community rehabilitation[91] and charity services[134].

Clinical commentaries

Three of the four clinical commentaries studied athlete TBI populations [113,130,131], and the last a military TBI population [132].

One study focused on the role of one specific discipline, physiotherapy, in the management of athletes with concussion[130]. The other three studies presented a more multidisciplinary perspective. In all four, the idea of phases of care transpired, with a focus on protection from further damage and monitoring in acute stages, followed by a rehabilitation phase. In all cases, care coordination and planning were central. The importance of assessing and managing symptoms within the broader context of patient personal, social and environment context was highlighted [113,131,132]

Randomized Trials

Four randomized trials investigated Treatment As Usual (TAU) conditions [169-172]. All trials studied TBI in the general population. TAU generally consisted of discharge instructions about symptoms and warning signs for more serious injuries but did not include systematic follow-up.

Case reports

Eleven case reports presenting a total of 12 cases were included [118-128]. Information relating to stakeholders and levels of care were extracted and included in the models below (Figure 3.6, Figure 3.5). A detailed analysis of these case reports is presented in Chapter 4.

ELEMENTS OF A CARE PATHWAY

Information about typical recovery timeframe was retrieved from 51 studies. Timeframe retrieved from studies including mixed populations were excluded, where data on different groups (i.e. paediatric and adults populations) were not presented separately. Average author-defined "typical" recovery was 63.4 days for general populations (N=27), 70 days for military populations (N=6) and 25.5 days for athletes (N=16).

Studies included in this scoping review highlight two core messages: i) P-TBI-S care typically involves a wide range of specialists and needs to be coordinated effectively and ii) it may take some time and multiple referrals for patients to access the right combination of specialists.

A list of stakeholders and care settings presented as part of a desired care pathway or natural care journey for people with P-TBI-S following TBI was extracted from the papers included in this review. These elements were used to generate 2 distinct components of a care pathway for people with P-TBI-S following TBI: a diagram of key stakeholders (Figure 3.5), and a blueprint of a comprehensive care system based on the slinky model [5] (Figure 3.6).

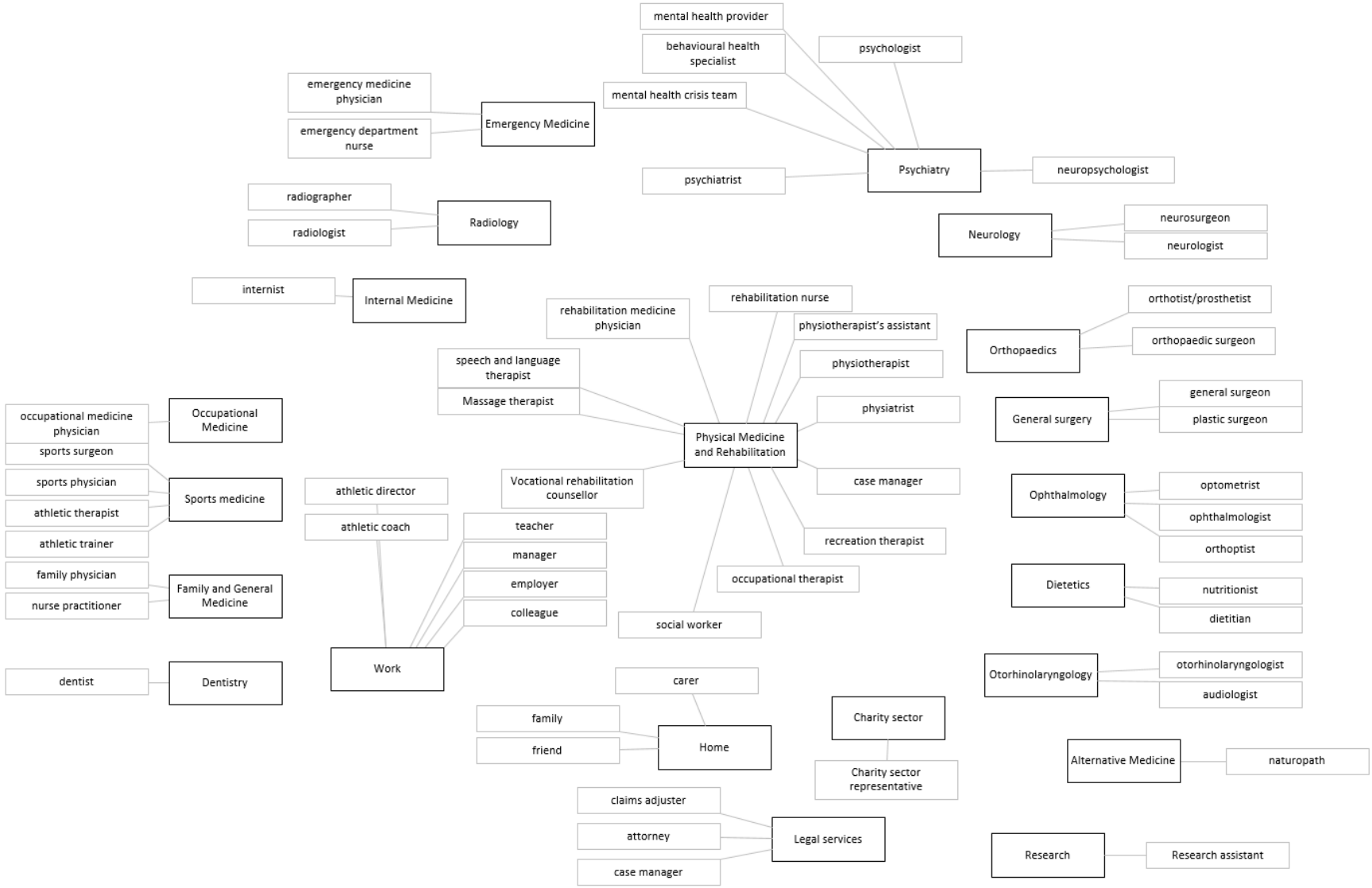


Figure 3.5. Stakeholders

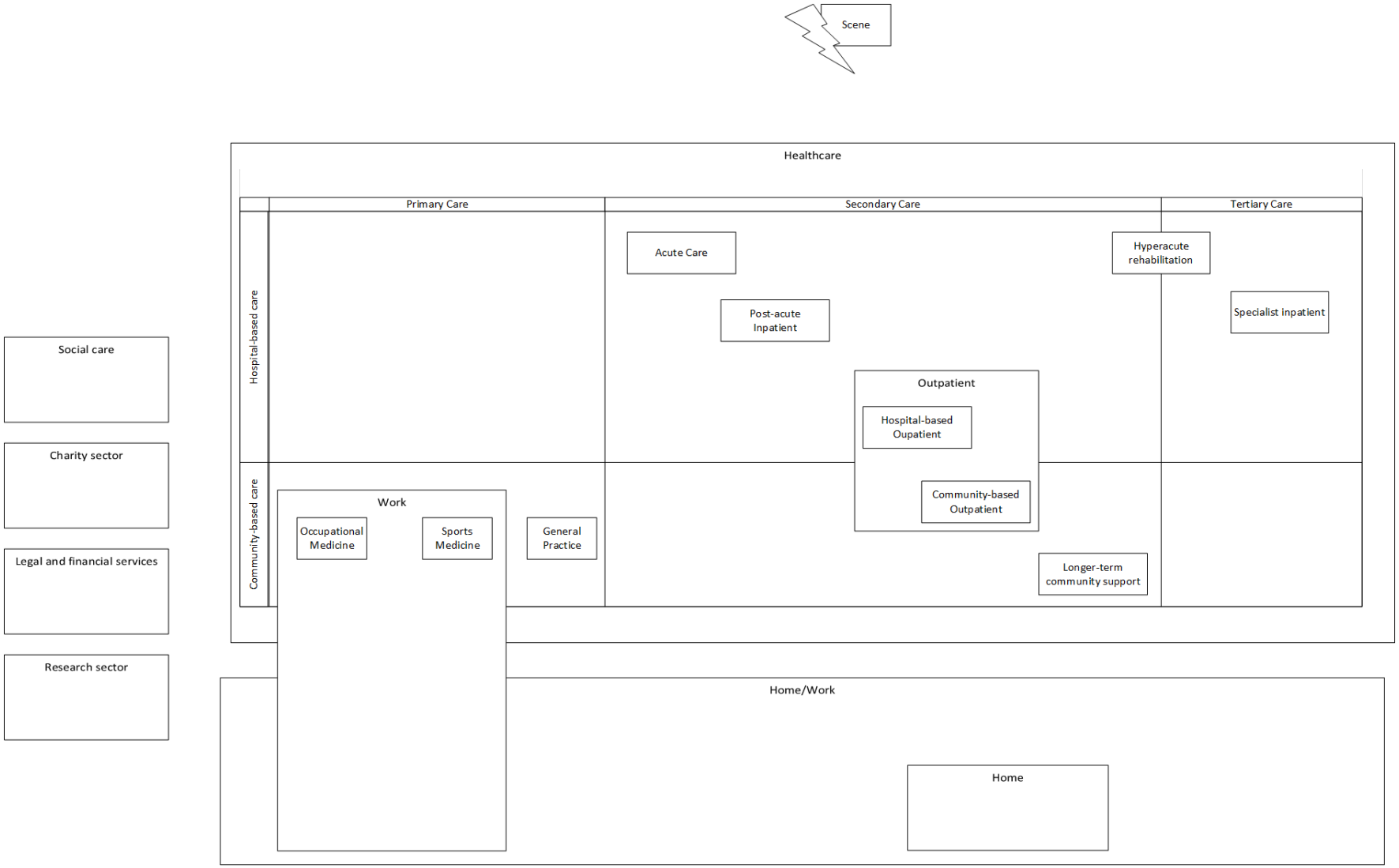


Figure 3.6. Levels of care

DISCUSSION

This review shows a general lack of evidence to guide P-TBI-S care. This can be explained by two factors.

Complexity of P-TBI-S

First and foremost, P-TBI-S is complex: its authenticity has long been debated and its aetiology remains unclear [153,196,199,201,202]. Consequently, its management is palliative and stratified: it aims to address the symptoms of TBI directly rather than their root cause, and the approach to treatment follows a stepped pattern. First line is typically conservative "watchful rest" [169-172,174,182,186,188,197,199]. When symptoms persist beyond the ill-defined "typical" recovery window, they are addressed individually [173,175,178-180,183-186,188-190,192,196,199].

This approach assumes that patients will seek help when they experience lasting symptoms. This is questionable considering that impaired cognitive functioning including lack of insight and difficulties with decision-making is a cornerstone of P-TBI-S [133,172]. It also assumes that patients have sought medical care at the time injury, have been diagnosed, and have received information about what to expect after their injury [196,203].

There is no systematic follow-up for patients discharged from emergency departments with uncomplicated mTBI. Follow-up is more widespread in athlete and military populations, for whom medical clearance is a prerequisite to return to play and return to duty respectively [176,177,181,182,193]. For the general population, routine follow-up was formerly recommended, although this is no longer the case [10,183,204]. However, some argue that the minority of patients who would benefit from routine follow-up get outweighed by the majority of people who do not in studies evaluating the efficacy of routine follow-up [172].

Because the symptoms associated with P-TBI-S are so numerous and varied, it is not uncommon for patients to have to manage multiple appointments and relay information between different specialists [135]. These silos of care, which are common in populations with complex needs, can lead to poor outcomes and extended use of healthcare resources [145,192,205]. Therefore, it is not difficult to see why patients with P-TBI-S easily falls through the gaps of care [115,185,206].

Typically, it is only after symptom-based management has been found to be ineffective that individualised, coordinated and holistic multidisciplinary care is considered [64,113,130-132,143,151,155,156,173,175,177-182,184-186,188-190,192,195,197,198,200]. Although evidence seems to suggest this approach to be the most suited for protracted TBI recovery, there is no consensus [10]. It is also unclear which disciplines should form the core of a multidisciplinary team, and

whether care should be dispensed through integrated multidisciplinary clinics or dispersed but coordinated service providers.

Methodological limitations

Another cause for the lack of guidelines for P-TBI-S care is the methodological limitations of the research. A large share of the papers included in this study were specific to athlete and military populations. Variation in demographic feature, nature of injuries, and range of complicating factors lead to compartmentalised care recommendations.

Beyond these, definitions of P-TBI-S (largely referred to as 'Post-Concussion Syndrome (PCS)' in the literature) and TBI, and any relationship between the two are unclear. "PCS" generally refers to symptoms lasting beyond the typical recovery timeframe, although that is sometimes considered to be "persistent PCS" or "chronic PCS", with "PCS" denoting immediate post-injury symptoms [143,144,170]. This is further complicated by the lack of consensus about what is considered a "typical" recovery timeframe. "Concussion" is often used interchangeably with "mild TBI", although it is sometimes considered to be a milder form of mTBI [200]. Some authors prefer to use "head injury" instead of "brain injury" and "mild" instead of "minor" [133] [183] [4,207]. P-TBI-S is typically associated with milder forms of TBI, even though it has been shown that its emergence is independent of initial injury severity [9,173].

Another methodological limitation to investigating care pathways and journeys for people with P-TBI-S is the lack of population-based longitudinal cohort studies and the biases in recruitment sites: typically, emergency departments and clinics for prospective studies, and medical record databases for retrospective studies. These three main methodological limitations have been highlighted in the wider TBI literature[3,6,8,19]

Limitations of scoping review

This review of the literature was conducted using a scoping review methodology, hence the quality of the research identified was not appraised. Thus, the included studies may provide low levels of evidence. The inconsistent terminology relating to TBI and P-TBI-S used in the field (Chapter 1) has complicated the search process. Although efforts were made to use wide terminology and refine search terms through multiple iterations of the search, it is possible that papers using less common terminology were not identified. Finally, only studies in English and French were included. Although language filtering was done manually at the screening stage, the search was carried out in English, so any work for which at least the title and abstract was not available in English will not have been retrieved.

Clinical relevance of this scoping review

This review shows a paucity of evidence supporting the design and implementation of care pathways for people with P-TBI-S. While a wide variety of healthcare professionals may be involved in the care of people with P-TBI-S, there is insufficient evidence to recommend that all patients benefit from a multidisciplinary input. There is also not sufficient evidence to recommend that all people with mild TBI should access rehabilitation. The current management of mild TBI relies on a "watch and wait" approach combined with symptom management interventions. The relative weakness of the evidence base limits development of effective care pathways. This does not mean that effort to define care pathways for the rehabilitation of people with P-TBI-S should be abandoned. Indeed, there are similarities in the services accessed and stakeholders involved in the care of this patient population. This suggests that there may be substantial overlap in their care needs. The development and implementation of robust care pathways could ensure that these are systematically addressed.

CONCLUSIONS

In this chapter, the current evidence base surrounding care for people with P-TBI-S was explored. The aims were to answer 3 main questions:

1. What are the care pathways for the rehabilitation of people with P-TBI-S?
2. What are the care journeys of people with P-TBI-S?
3. What methodological approaches are used to explore care journeys?

The findings from this review highlight the paucity of the evidence regarding care pathways for this patient group. Recommendations for care beyond the acute settings are limited, and few studies explored care journeys for large and diverse patient cohorts. The main methodological approaches used to explore care journeys and care pathways were cohort studies, which were often confined to specific subgroups of the TBI population. This review however highlighted that other types of evidence, in particular case reports, may be useful in exploring care journeys in detail in a more varied group of patients with P-TBI-S.

The findings from this chapter point to the need for a more detailed exploration of these case reports in order to explore the care journeys, care needs, and stakeholders involved in the care of people with P-TBI-S. This more detailed exploration of case reports is presented in Chapter 4.

CHAPTER 4 – CASE REPORTS

The previous chapter proposed a review of the literature to identify research exploring care pathways and care journeys for people with P-TBI-S. Whilst the evidence for defined care pathways beyond the acute setting, and research exploring care journeys in the wider community of patients with P-TBI-S was limited, case reports stood out as a source of information rich in detail about the care journeys of people with P-TBI-S. In this chapter, the case reports extracted from the scoping review (Chapter 3) are explored to identify points of convergence and divergence in the care journeys of a heterogeneous group of patients, explore their care needs, and identify core stakeholders who may be involved in the care and support of these people.

Figure 4.1 highlights the place of this study within the broader structure of this thesis.

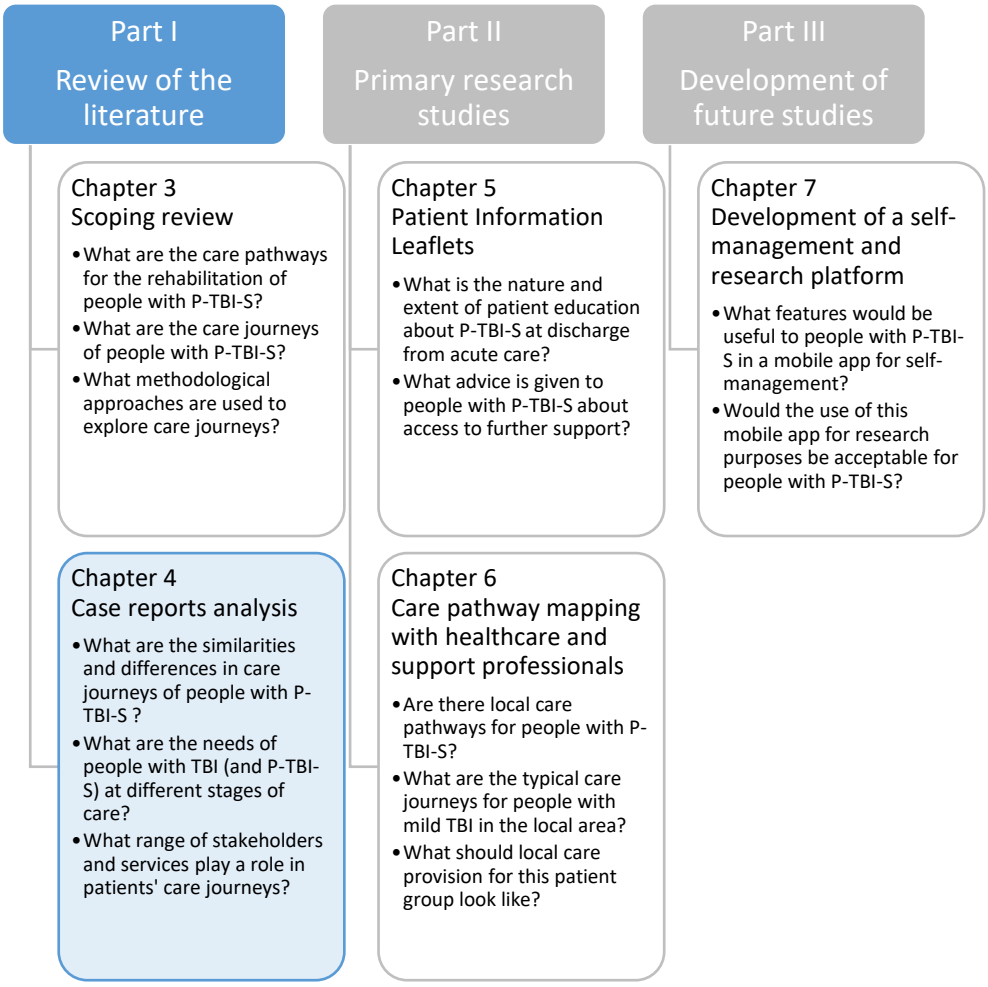


Figure 4.1. Chapter 4 within thesis structure

BACKGROUND

TBI: AN INTERNATIONAL PROBLEM

Traumatic Brain Injury (TBI) is a major and growing global public health problem. Although reports of incidence vary greatly, even conservative estimates advance that throughout the world between 100 and 300 per 100,000 people sustain a TBI each year [72,73]. Robust epidemiological data on TBI is scarce, as people with mild TBI, which represents 80 to 90% of all TBIs, do not always seek medical attention [77]. Mild TBI (mTBI) alone is thought to be more prevalent than cancer, Acquired Immunodeficiency Syndrome, multiple sclerosis and spinal cord injury combined [19].

TBI is a complex condition resulting from a range of mechanisms of injury and affecting a wide spectrum of the population, with peaks for young adults and the elderly [4,71]. It is generally considered a self-limiting condition; however, its sequelae can be long lasting, regardless of initial injury severity [9]. Symptoms persisting following TBI as part of a Post TBI

Syndrome (P-TBI-S) are largely non-specific, and include cognitive dysfunction, sleep disturbance, emotional changes, and physical difficulties. These symptoms may only emerge when environmental demands are high, may not be apparent immediately after the injury, and their progression is not linear [8,9,57,77]. This can make it difficult to link the presenting symptoms with the initial TBI, and therefore represents a challenge in referring patients to appropriate care services in a timely manner.

While the direct and indirect healthcare costs of TBI are modest compared to other neurological conditions, its indirect societal costs are disproportionately high [83]. The increasing global population coupled with advances in medicine have led to a rise in the incidence of TBI as well as in the prevalence of people surviving their injury and living with its long-term and potentially incapacitating consequences [4,208]. The growing impact of TBI warrants the need for better care and, given the long-term consequences it may bring forth, the development of appropriate evidence-based rehabilitation services for this patient population.

IDEAL P-TBI-S PATHWAYS

Guidelines are numerous and specific for the assessment and management of acute TBI; however, rehabilitation guidelines are scarce [209]. The National Institute for Health and Care Excellence guideline for the assessment and management of head injury presents limited recommendations for post-acute care [26]. The Royal College of Physicians' guideline for Acquired Brain Injury (ABI) rehabilitation remains is non-specific in the context of TBI, and recommendations are largely driven by symptoms presentation [5].

Symptom-driven recommendations make it difficult to view TBI rehabilitation through an integrated care lens. Integrated care frameworks are useful to describe complex care processes as they can highlight gaps in care provision. The commonly used "slinky" model of rehabilitation proposes an idealised rehabilitation pathway for ABI in which patients transition progressively from hospital-based to community-based care settings [5]. This model also incorporates an opportunity to re-access more acute services as needed once patients reach longer-term community support. Finally, each level of care is associated with specific goals and outcomes, from reducing impairments to improving activity and enhancing participation.

UNCLEAR CARE TRAJECTORIES AND VALUE OF CASE REPORTS

The sequelae of TBI are variable in both nature and intensity, largely unpredictable from acute assessments, and recovery is generally non-linear [210,211]. To date, studies on TBI have

mostly focused on subgroups of patients in specific contexts, leading to findings that cannot be generalised to the wider TBI population [3,6] (Chapter 3).

In addition to substantial sampling bias, the lack of long-term population-based cohort studies in TBI represents another significant barrier to understanding patients' rehabilitation trajectories [3,6]. Documenting learning from patients' care journeys can lead to greater understanding of the current state of TBI care across the continuum. It allows the identification of strengths and shortcomings in support services, particularly the pathways between hospital and community-based services. In the context of TBI rehabilitation pathways, case reports are particularly useful as they often mirror clinical thinking processes and can offer detailed information about heterogeneous presentation, diagnostic procedures and outcomes [212,213]. Case reports recount both the successes and the failures of procedures in place for given patient populations, and therefore reinforce the idea that one-size fits-all approaches will leave some patients to fall through the gaps [214-216].

RESEARCH OBJECTIVES

There are no guidelines for the rehabilitation of patient with P-TBI-S, although the review of the literature suggested that these patients may require some rehabilitation (Chapter 1, Chapter 3). Currently rehabilitation input is provided on an as-needed basis, although there are similarities in the services accessed. This suggests that there may be room for the development of care pathways (Chapter 3).

In an effort to further understand care journeys and to determine which services should be in place to ensure optimal outcomes for patients with P-TBI-S, the case reports included in the scoping review (Chapter 3) were extracted and analysed in detail. The aim of this study was to evaluate whether accounts of patients' care journeys can be used to identify core elements of a care pathway.

Case reports emerging from the review were extracted and analysed in order to investigate the care journeys of patients presenting to healthcare services with persisting symptoms following TBI by addressing three research questions:

1. What are the care journeys of people with P-TBI-S?
2. What are the needs of people with TBI (and P-TBI-S) at different stages of care?
3. What range of stakeholders and services play a role in patients' care journeys?

METHODS

SELECTION OF PAPERS

Published case reports were extracted from the scoping review investigating care journeys for people with P-TBI-S presented in Chapter 3. Eleven papers, which presented 12 cases, were included in the study (Table 4.1).

Table 4.1. Case report papers

ID	Author	Title	Number of cases
1	Bader & Thompson (1993)[119]	The year after: post-concussion syndrome	1
2	Finn & Waskiewicz (2015) [120]	The role of occupational therapy in managing post-concussion syndrome	1
3	Garcia-Baran et al. (2016)[121]	Therapeutic approach of a high functioning individual with traumatic brain injury and subsequent emotional volatility with features of pathological laughter and crying with dextromethorphan/quinidine	1
4	Hamson-Utley et al. (2017) [122]	Managing mental health aspects of post-concussion syndrome in collegiate student-athletes	1
5	Knollman Porter et al. (2014)[123]	Speech-language pathology and concussion management in intercollegiate athletics: the Miami University Concussion Management Program	1
6	Lambru et al. (2009) [124]	Post-traumatic cluster headache: from the periphery to the central nervous system?: clinical notes	1
7	Lewis & Lucas (2012)[125]	Understanding mild traumatic brain injury and postconcussion syndrome	1
8	Mateer (1992) [118]	Systems of care for post-concussive syndrome	1
9	Olver (2005) [126]	Traumatic brain injury: the need for follow up	2
10	Stone et al. (2016)[127]	Functional Disorders in Neurology: Case Studies	1
11	Turner et al. (2018) [128]	Adapting cognitive processing therapy to treat co-occurring posttraumatic stress disorder and mild traumatic brain injury: a case study	1

DATA EXTRACTION

Data extraction was conducted in two stages.

The first stage focused on individual care journeys. Care journeys were mapped onto the level of care model derived from the scoping review (see Figure 3.6 in Chapter 3). Data relating to care journeys were extracted from each case report. Data points included timeframe indicators and services accessed. These were used to map individual patient journeys, which were then aggregated using the level of care model. Data relating to the stakeholders encountered at different stages of care were also extracted.

The second stage involved coding the data using the International Classification of Function, Disability and Health (ICF) [54]. A database was created in Microsoft Excel to break down the case reports into the smallest meaningful units, or data points. Each unit was then assigned

corresponding ICF codes falling into one of the four domains: Body Functions, Body Structures, Activities and Participations, and Environmental Factors. The ICF factors extracted from the case reports were then compared against those present in the ICF core sets for TBI (comprehensive, TBI-CS) and rehabilitation (R-CS) [217-221].

The comprehensive TBI-CS contains 139 factors, 23 of which are included in the brief version. The R-CS contains 30 factors, all of which are included in the comprehensive TBI-CS. The comprehensive TBI-CS contains 3 Environmental Factors at the third level of classification: e1100, e1101 and e1108. For analysis, they were substituted for e110. The total number of comprehensive set factors was therefore 137. ICF factors included in the R-CS, comprehensive TBI-CS and brief TBI-CS are listed in Appendix 4.1.

Each unit was the smallest relevant piece of information relating to healthcare settings, stakeholders encountered, symptoms, item pertaining to activities and participation in activities of daily living, etc. For example, the sentence "When I was trying to do paperwork, I would forget what I was supposed to be writing down" [222, p.251] contains 3 units linking to 3 ICF codes:

Section	**Detail**	**ICF code**
"When I was trying to do paperwork"	This relates to work in the context of this case	d850 (remunerative employment)
"I would forget"	Memory issues	b144 (memory functions)
"Writing down"	Activity/functioning relating to writing	d170 (writing)

DATA ANALYSIS

Data from individual maps relating to movements between different levels of care were aggregated to highlight the common routes of care. The strength of links between services was calculated by counting the total number of times patients transitioned between any two levels of care. Key stakeholders throughout the care journeys and at different levels of care were identified. The frequency of reported ICF factors between the different cases and settings was explored.

OVERVIEW OF CASES

Twelve case reports were included, describing various levels of TBI care for 7 females and 5 males. The age of patients was specified in 11 reports and ranged from 20 to around 50. The modes of injury were varied and included 5 Road Traffic Collisions (RTCs), 3 object strikes, 2 Sports-Related Concussions (SRCs), 1 assault and 1 fall. The severity of the TBI was mild in the 10 reports that mentioned it. Injury severity was generally determined based on acute presentation including Glasgow Coma Scale score, loss of consciousness, posttraumatic amnesia and imaging findings. The scope of timelines covered was variable, ranging from 1 to 8 months (average 3.63 months), and one covered 19 years. Case characteristics are summarised in Table 4.2.

Table 4.2. Summary of case characteristics

F=Female; M=Male; RTC=Road Traffic Collision; SRC=Sports Related Concussion; n/s=not specified

Paper ID	Age	Gender	Mode of Injury	TBI severity	Approximate timeframe
1	n/s	F	RTC	Mild	3 months
2	41	F	RTC	Mild	8 months
3	34	M	Assault	n/s	5 months
4	21	M	SRC	Mild	1 month
5	20	F	SRC	Mild	1 month
6	48	F	Object strike	Mild	19 years
7	Early 50s	F	Object strike	Mild	6 months
8	47	M	RTC	Mild	3 months
9	24	F	Fall	Mild	1 month
9	38	M	RTC	Mild	1 month
10	22	M	Object strike	n/s	3 months
11	50s	F	RTC	Mild	8 months

MOVEMENTS BETWEEN SERVICES

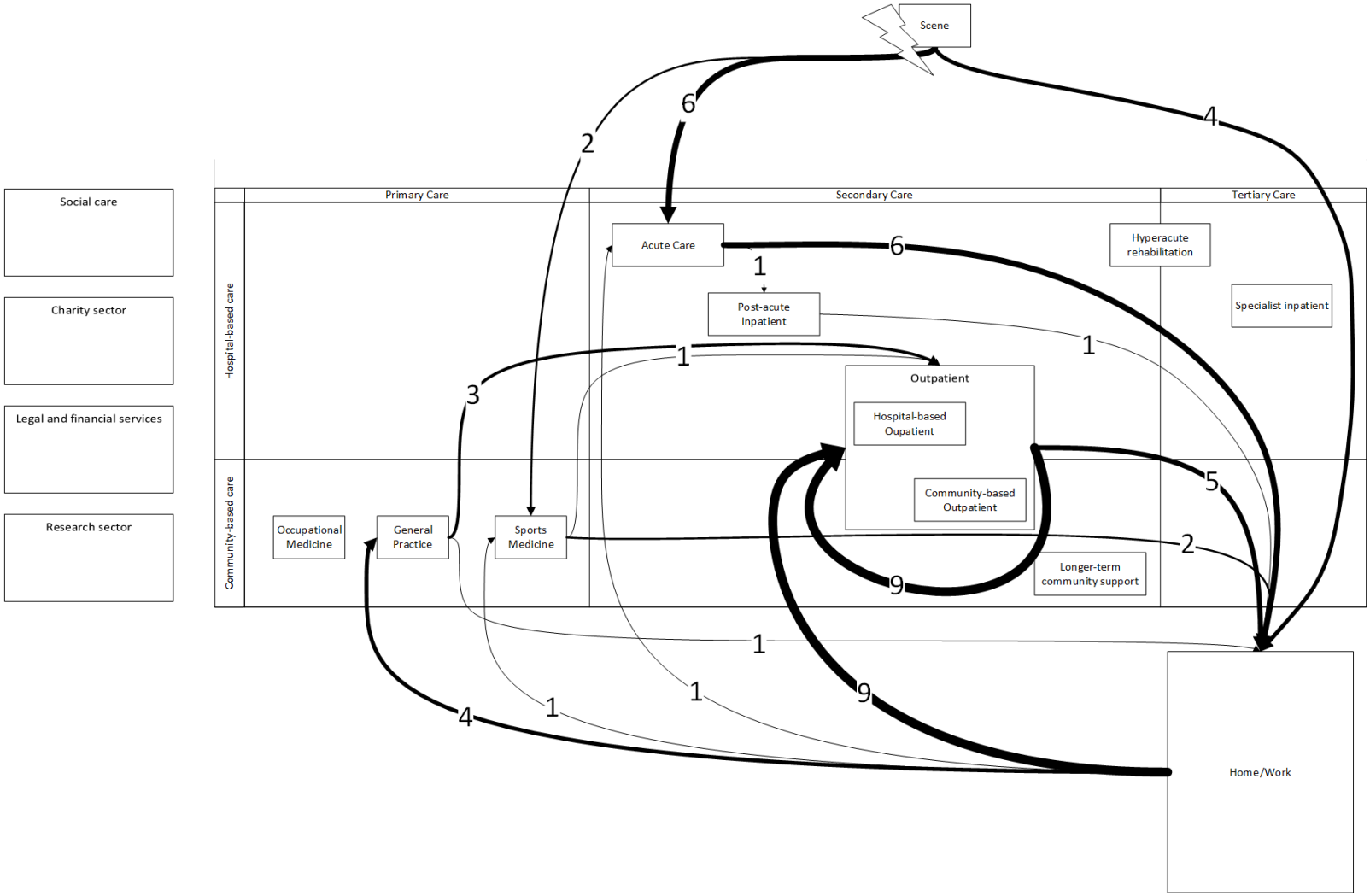


Figure 4.2. Aggregate map of patient journeys through levels of care

Each number refers to the number of mentions of a route in the 12 case reports

KEY STAKEHOLDERS

A list of 25 stakeholders was extracted, including 16 Healthcare Professionals (HCPs), 5 work relations, 3 personal relations and 1 other from the reports. HCPs encountered in the patient journeys included: clinical psychologists, neuropsychologists, psychiatrists, surgeons (general, neuro, orthopaedic, plastic), internists, neurologists, otolaryngologists, nurses, occupational therapists, physiotherapist, speech and language therapists, GPs, and team physicians (for athletes). Work relations included managers, academic instructors, athletic team trainers, colleagues and teammates. Personal relations included family (parents, partners) and friends. The other stakeholder group identified was insurance companies' representatives. The stakeholders most commonly referenced in the case reports were neurologists (N=7), family members (N=6) and neuropsychologists (N=4). The outpatient setting comprised the widest variety of stakeholders (N=11), spanning the HCP, personal and work relationship groups.

OVERVIEW OF FUNCTIONING, DISABILITY AND HEALTH

A total of 80 unique ICF factors were identified in the dataset: 34 Body Functions, 10 Body Structures, 21 Activities and Participation, and 15 Environmental Factors. A complete list of identified factors is presented in Appendix 4.2. Fifty-six of the 80 factors are present in the TBI comprehensive core set (Table 4.3).

Table 4.3 ICF factors at different stages of care and presence in the comprehensive TBI-CS

TBI-CS=Traumatic Brain Injury Core Set

Setting	Number of factors	Number of identified factors present in the comprehensive TBI-CS	Percentage of identified factors present in comprehensive TBI-CS
Scene	21	18	85
Acute	12	7	58
Inpatient	3	2	66
Outpatient	60	42	70
Primary Care	47	39	82
Home/Work	11	10	90
Unknown	4	4	100
All settings	**80**	**56**	**70**

Most factors (51/80) were only present in one or two cases. Only 11 factors were present in the majority (7 or more) of cases (Table 4.4). All these factors were present in the comprehensive TBI-CS, 64% (N=7) in the brief TBI-CS and 45% (N=5) in the R-CS. No factor was present in all 12 cases.

Table 4.4. Factors present in more than half the cases

TBI-CS=Traumatic Brain Injury Core Set; R-CS=Rehabilitation Core Set; b=body functions; s=body structures; d=activities and participation; e=environmental factors

Code	Description	Number of cases	Comprehensive TBI-CS	Brief TBI-CS	R-CS
b280	sensation of pain	11	✓	✓	✓
e355	health professionals	10	✓	✗	✗
b110	consciousness functions	10	✓	✓	✗
e580	health services, systems and policies	9	✓	✓	✗
b140	attention functions	9	✓	✓	✓
b144	memory functions	9	✓	✓	✗
b152	emotional functions	9	✓	✓	✗
s710	structure of head and neck region	8	✓	✗	✗
d570	looking after one's health	7	✓	✗	✓
d850	remunerative employment	7	✓	✗	✓
b130	energy and drive functions	7	✓	✓	✓

When considering setting separately, these main factors only emerged in a majority of cases at the scene of the TBI, in outpatient settings, and at home or work (Table 4.5).

Table 4.5. Most common factors by settings

TBI-CS=Traumatic Brain Injury Core Set; R-CS=Rehabilitation Core Set; b=body functions; s=body structures; d=activities and participation; e=environmental factors

Setting	Code	Description	Number of cases	Comprehensive TBI-CS	Brief TBI-CS	R-CS
Scene	b110	consciousness functions	9	✓	✓	✗
	s710	structure of head and neck region	7	✓	✗	✗
Outpatient	e355	health professionals	8	✓	✗	✗
	e580	health services, systems and policies	7	✓	✓	✗
Home/Work	b280	sensation of pain	10	✓	✓	✓
	b144	memory functions	7	✓	✓	✗
	d850	remunerative employment	7	✓	✗	✓

The number of factors identified varied by setting. Only 3 factors were associated with inpatient settings. The home and outpatient settings showed the widest range of factors with 47 and 60 respectively. The proportion of Body Functions and Activities and Participation was higher in the home, outpatient and primary care settings and at the scene than in the acute and inpatient settings (Figure 4.3).

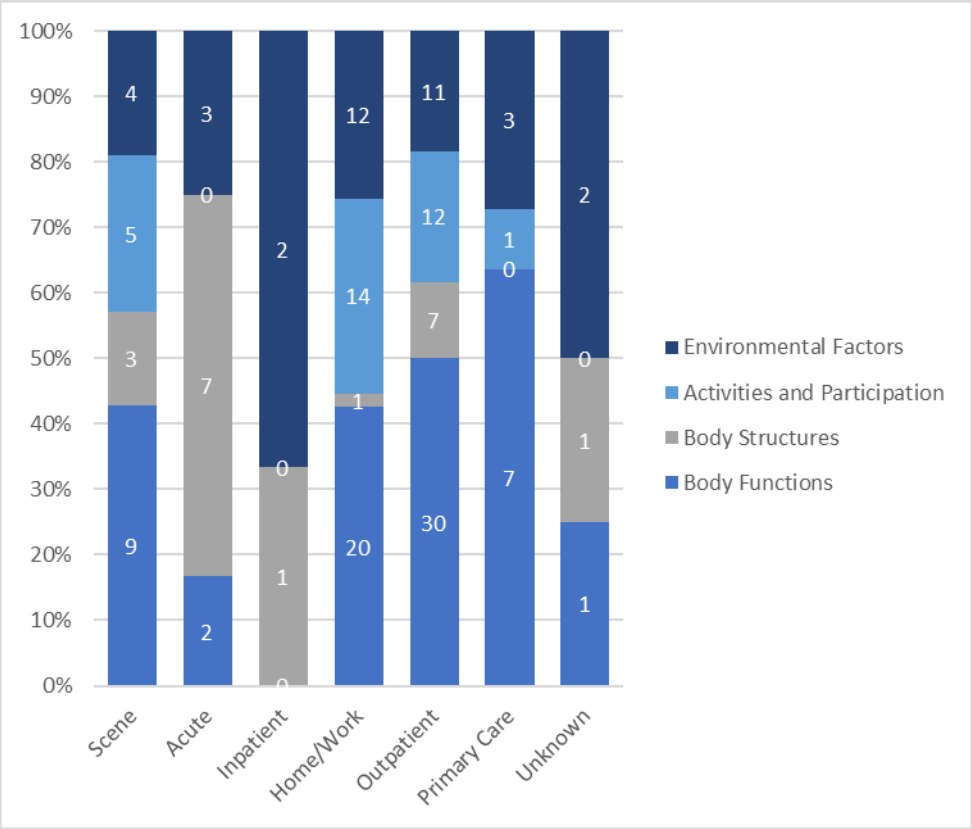


Figure 4.3. Number of factors and domain distribution by setting

The comprehensive TBI-CS is well aligned with the data. 70% of ICF factors identified in the dataset are present in this set. It performs particularly well for Activities and Participation (90% match) and Environmental Factors (87% match). 65% of the Body Functions identified in the data are present in the set. Only 20% of the body structures identified in the data are present in the set. The performance of the TBI-CS is relatively homogeneous throughout the different care settings, but performs least well in Acute Care (58%). The detailed performance of the brief and comprehensive TBI-CS and the R-CS for this data set is presented in Appendix 4.3.

DISCUSSION

Two features stand out from this study. Firstly, the relatively large number of unique ICF factors identified in this dataset, testifying to the complex nature of TBI [210,211]. Secondly, the

frequency of re-entry into the healthcare system, which suggests that patient needs are not always met efficiently or effectively.

It is unclear whether these two findings can be linked in an explanatory way. One interpretation is that the number of potential difficulties experienced by TBI patients is so high that it is not possible to design a pathway and services that meet their needs. However, there are reasons to think this interpretation is simplistic.

While half of identified factors are included in relevant core sets, those that are not are more commonly found in the early part of the care journey. It seems that the absent factors may be attributable to co-morbid trauma, such as abdominal or chest injuries. Despite the greater number of factors absent from the core sets in the early part of the journey, care in the hospital settings was relatively streamlined. This smooth movement of patients through acute care might be expected considering the focus on early management in TBI care guidelines [26,60].

Variation in patient profiles is one of the justifications for the paucity of TBI care recommendations in the post-acute settings [209,223]. This study, however, suggests that variation in patient profiles is greater in earlier parts of the journey, possibly because of the propensity of TBI to occur in a polytrauma context. In the later part of the journey, there is a higher proportion of common features, which can be used as the basis for the design of unified medium- to long-term care. Despite this finding, almost a third of the total number of factors still are not included in the core sets. This may be because case reports are not representative of the general TBI population. However, it is these atypical patients who present the greatest pathway challenge: relatively small numbers of patients with relatively uncommon presentations can use surprisingly large amounts of resource as they try to find the support they need. Therefore, within a unified care pathway, there should be the expertise and capacity to care for those with complex or unusual needs.

The existence of re-entry loops was a core feature of this study. Some patients who did not seek medical advice following their injury, or who were discharged home from emergency services, eventually reached out for help due to P-TBI-S. This reinforces the importance of opportunities for re-access proposed in the “slinky” model (Chapter 1). These findings are aligned with evidence highlighting the high potential for patients with P-TBI-S to fall through the gaps of healthcare provision [199,224,225]. High use of re-entry loops could indicate less than optimal service design. The biggest loop in this study was between out-patient care and return to home. Increasing transitional support between out-patients and full community reintegration should diminish this re-entry loop [226].

A wide variety of stakeholders was identified along the various TBI care journeys, a majority of which were HCPs from a range of specialties, particularly varied in acute care. Professional relations, including work colleagues and managers, were not only identified in the "home/work" setting, but also in the "out-patient" care setting, suggesting that vocational rehabilitation should be a core part of the later stages of rehabilitation. These findings suggest that in addition to appropriate medical expertise, the patients' social context should be a focus point of their care plans and should be factored in from early rehabilitation settings through to full discharge from care services.

The use of TBI case reports is valuable as it can highlight both the successes and failures of current care practices, as well as present new discoveries and rare observations [227]. The examination of case reports in this study generated rich information related to functioning and care journeys, and provided an opportunity to explore an area where evidence is lacking. They are a useful indicator of the variability of care journeys while highlighting points of convergence and divergence in the movements between care services. The use of the ICF enabled the synthesis of apparently disparate cases, and generated transferable findings. The ICF could be used at local and regional level to plan services and to measure functional outcome in heterogeneous patient groups.

However, the information presented in case reports may be incomplete, generally focus on a specific angle for the presentation of a case, and might omit information that would otherwise be valuable. The small sample size and the variability in the range of timelines and patient profiles did not allow for direct comparisons between cases. In this study, one of the case reports focused on deep brain stimulation for the treatment of depression in a patient with post-traumatic parkinsonism: as such, the narrative focused on later stages of rehabilitation while giving limited detail on acute management of a patient with atypical TBI sequelae. Another report focused on a specific concussion management programme: it is possible that other services accessed by the patient were not recounted in the report. Similarly, reporting bias may explain the lack of access to longer-term community support apparent in this study. As the case reports included in this study were extracted from the scoping review presented in Chapter 3, their quality was not formally appraised using quality assessment tools. By definition, case reports are uncontrolled study designs, therefore few formal quality assessment tools are available [228]. The aim of this study was to evaluate whether case reports represent a useful source of information when investigating issues where research with higher levels of evidence is limited. Due to the paper selection process, where case reports were extracted from a broader scoping review search, it is possible that not all relevant case reports were identified. This study highlights the value of case reports in investigating care journeys and care pathways for people with P-TBI-S. This suggests that a more detailed exploration of the case reports literature would be valuable.

To increase rigour. such work should include a search process specifically looking for case reports study designs, and should be combined with a critical appraisal tool (such as the Joanna Briggs Institute critical appraisal checklist for case reports [229] to assess the quality of the reports.

Current guidelines for the rehabilitation of TBI are scarce, and generally rely on addressing specific symptoms as they emerge post-injury. There is currently no framework to address specific rehabilitation needs in a global TBI context. This study suggests that clinical services that meet the rehabilitation needs of most patients with TBI can be developed. These services ought to focus on functional needs assessment at discharge from acute care, and support transition to community reintegration including work. Using the ICF to capture the rehabilitation needs in a patient cohort would allow journey mapping and service design, which would contribute to the development of individually tailored pathways.

In conclusion, this analysis of case reports provides useful insights into the functioning of people with TBI, the potential service solutions, and can help inform the design of a framework for further exploration of care journeys using more robust research methods.

CONCLUSIONS

The work presented in this chapter aimed to address 3 questions through the exploration of case reports extracted from the scoping review (Chapter 3):

1. What are the care journeys of people with P-TBI-S?
2. What are the needs of people with TBI (and P-TBI-S) at different stages of care?
3. What range of stakeholders and services play a role in patients' care journeys?

The results from this study showed the complexity and variability of patient care journeys in a complex care system. However, it also highlighted that even heterogeneous patients with P-TBI-S share common features, largely aligned with the understanding of the impact of TBI on functioning. A wide range of stakeholders involved in the care and support of these people was identified, but there was notable overlap in these between the different patients.

The paucity of information regarding care pathways in the literature does not necessarily imply that protocols for the management of these patients are not in place in clinical practice. Part II of this thesis will explore current practice to further the understanding of care patient care journeys, uncover any existing care pathways and identify the elements that will enable the development of robust care pathways for the rehabilitation of people with P-TBI-S.

PART II: Primary Research

Part I set out to explore the literature on Post Traumatic Brain Injury Syndrome (P-TBI-S) rehabilitation.

The scoping review (Chapter 3) showed that there are no defined care pathways for people with P-TBI-S. There was also a lack of research looking at care journeys across multiple levels of care. A large share of the studies coincidentally reported information pertaining to care pathways and journeys, but few set this as a primary research objective. Cohort studies used either prospective or retrospective designs to look at patients' care journeys, but the inclusion criteria were strict, and scope was limited. The findings from these studies were therefore largely non-generalizable. In spite of the lack of rehabilitation guidelines, or studies that would form a strong basis for the production of such guidelines, the scoping review highlighted that people with P-TBI-S may require some level of rehabilitation input, which is currently provided on an as-needed basis. The review also showed similarities in the services accessed by people with P-TBI-S. These findings suggest that there may be room for the development of care pathways guiding care for this group.

A detailed analysis of case reports (Chapter 4) showed that care journeys for people with P-TBI-S are variable, particularly in later stages of care. It showed however that even patients with varied profiles have needs in common, which are in line with the current understanding of patient needs following Traumatic Brain Injury as testified by significant overlap between the need highlighted in the data and those present in the relevant core set of the International Classification of Functioning, Disability and Health. These needs were numerous but relatively homogeneous in later stages of care. This suggests that they may represent elements upon which to build care pathways beyond acute care. The range of stakeholders and services involved in the care journeys was broad. This highlighted the importance of ensuring access to a wide array of specialists and the involvement of stakeholders beyond healthcare professionals alone in care and care planning for people with P-TBI-S.

Overall, there is little literature on rehabilitation for people with P-TBI-S. Lack of focus on care pathways and methodological shortcomings result in a lack of guidelines overseeing care for this patient group. This lack of care pathways gives rise to gaps in the healthcare provision, through which some patients may fall. The rehabilitation needs of patients with P-TBI-S are varied, but there are some common elements, suggesting that a care pathway can be defined.

The lack of national guidelines does not necessarily imply that pathways are not in place at more local levels. As such, the aim of the work in part II was to explore current practice at national and local levels in search of care pathways, and to highlight gaps in local care systems.

Part II consists of two pieces of primary research investigating current practice to answer 5 research questions:

1. What is the nature and extent of patient education about P-TBI-S at discharge from acute care?
2. What advice is given to people with P-TBI-S about access to further support?
3. Are there local care pathways for people with P-TBI-S?
4. What are the typical care journeys for people with mild TBI in the local area?
5. What should local care provision for this group look like?

Chapter 5 presents an appraisal of discharge information distributed to patients with mild TBI discharged from A&E departments across England. Chapter 6 explores the perspectives of healthcare and support providers in Coventry and South Warwickshire on the state of care for people with P-TBI-S across different levels of care.

CHAPTER 5 – PATIENT INFORMATION LEAFLETS

In this chapter, the accessibility, availability and contents of information about mild Traumatic Brain Injury (mTBI) distributed to patients at discharge from A&E department in England is investigated.

Figure 5.1 highlights the place of this study within the broader structure of this thesis.

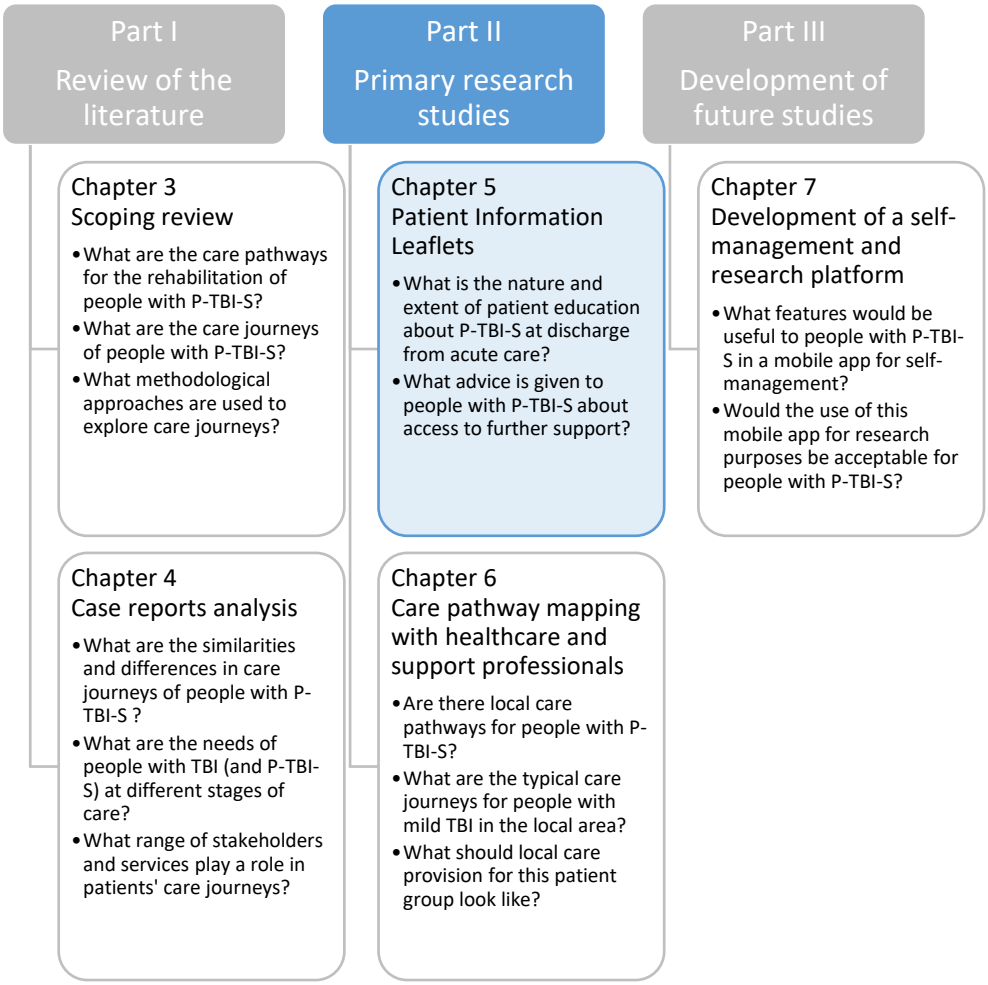


Figure 5.1. Chapter 5 within thesis structure

BACKGROUND

The review of the literature indicated that there is no systematic follow-up of patients who have had a mTBI in the UK. A large proportion of patients attending A&E with Traumatic Brain Injury (TBI) are discharged home as their injury is considered mild and they do not exhibit signs that would warrant their admission into hospital for observation or further care. In the majority of cases, patients who have had a mTBI will completely recover within a few weeks. A non-negligible proportion of this group however, will develop persisting symptoms following their injury which may warrant further care and support (Chapter 1).

Patient information is pivotal to care, and is a core part of the ethos of UK Department of Health: "no decision about me without me" [230, p.3]. As recommended in clinical practice guidelines, all patients discharged home from A&E should receive discharge instructions, and their GP should be notified. This provision theoretically ensures that patients understand the normal progression of TBI and promote health-positive behaviours to prevent further injuries and encourage treatment compliance, including help-seeking behaviour [231]. Nonetheless, a number of people with Post Traumatic Brain Injury Syndrome (P-TBI-S) fall through the gaps of care, which can have significant consequences for their reintegration into the community [115,185,206].

A scoping review of the literature (Chapter 3), including exploration of clinical guidelines, showed that current management of TBI is conservative in the first instance, and symptom-specific when P-TBI-S emerges. The review also showed the absence of TBI-specific rehabilitation care pathways, which was posited to be one of the reasons for patients falling through the gaps of care. In such a care structure, the responsibility therefore largely falls on the patients themselves to recognize problems warranting further care, and to seek appropriate support. This may lead to significant looping around services in community settings (Chapter 4).

This chapter explores the access to and the quality of the information available to patients who have had a mild TBI. The hypothesis was that patients may not have access to relevant information after their injury. This may lead to poor understanding of signs and symptoms warranting further care, and lack of knowledge about appropriate support services. This could be due to patients not receiving information, and/or patients not understanding the information received.

The A&E setting can often be chaotic, and contact with various health care professionals is typically transient [232]. This context can make it difficult for patients, and maybe particularly for those who have had a brain injury, to be receptive to any information given to them at that stage. To compensate for such barriers, discharge instructions should also be given to patients in written form [233(item 1.5.12, p.15),26(items 1.9.7 and 1.9.8, p.38)]. Studies have shown that Patient Information Leaflets (PILs) are helpful to enhance recall of what was said during a consultation and positively affect outcomes as patients find these useful to manage their health [234-237]. However, it is possible that patients are not always provided clear written discharge information [238-240].

In the UK, 16.4% of adults have an Organisation for Economic Cooperation and Development literacy level of 1 or below, defined as the Department for Business, Innovation and Skills as low proficiency. Given that the information presented in PILs is likely to be unfamiliar to patients, the recommended reading age is 11 to 12 years old [241]. Despite

this, many studies have shown that written information targeted to patients falls above this threshold [242-244], including information on the NHS website [245]. As such, patients may not understand discharge information, even when it is given to them.

RESEARCH OBJECTIVES

PILs are routinely distributed to patients and their relatives following discharge from A&E in England. However, these PILs are not standardised and are specific to each NHS Trust. Their development process is guided by evidence and local advisory groups, and redacted by expert clinicians. They contain information about a given condition, its expected progression and signs that should alert the patient and encourage them to seek further care.

The primary aim of this study was to explore advice given to patients following discharge from A&E departments throughout England and determine whether it is adequate to ensure people with P-TBI-S can find their way back to care and support services.

Two research questions guided this study:

1. What is the nature and extent of patient education about P-TBI-S at discharge from acute care?
2. What advice is given about access to further support for P-TBI-S?

The secondary aim of this study was to produce a PIL using key information from the review of the literature (Chapter 3) and the reviewed PILs. The resulting PIL will constitute a baseline of information to be implemented in a self-management app (Chapter 7) for TBI survivors.

IDENTIFICATION OF SOURCES AND SEARCH PROCEDURE

In 2010, a report from the National Audit Office on the state of major trauma care in England highlighted important disparities throughout the country in the quality of care and outcomes following major trauma. The report proposed the creation of regional trauma networks, with the aim of ensuring the availability of the full array of emergency care services relevant to major trauma care within a coordinated network of hospitals and ambulance services, where transfer of patients and information would be facilitated. As such, the creation of Major Trauma Networks (MTNs) would lead to the reduction of regional disparities in care by pooling resources, encouraging standardization of care and promoting best practice nationally [246].

MTNs are composed of Major Trauma Centres (MTCs) and associated Major Trauma Units (MTUs). A list of MTCs and MTUs was compiled using information available through the MTC trust websites, and/or specific websites for regional MTNs. There are 12 MTNs in England. Queen's Medical Centre Nottingham was identified as an MTC, but no information could be retrieved regarding any affiliated MTUs, nor was it linked to one of the 12 MTNs. For the purposes of this study, it was considered as a standalone MTC under a potential "East Midlands Trauma Network". Within these MTNs, there are 22 adult or adult and children MTCs. These are linked to a total of 123 MTUs, which span 120 NHS Trusts and NHS Foundation Trusts. The full list of MTNs, MTCs, MTUs and Trusts are presented in Appendix 5.1. Figure 5.2 shows the adult and adult & children MTCs and MTUs, which are the focus of this study, in each MTN.

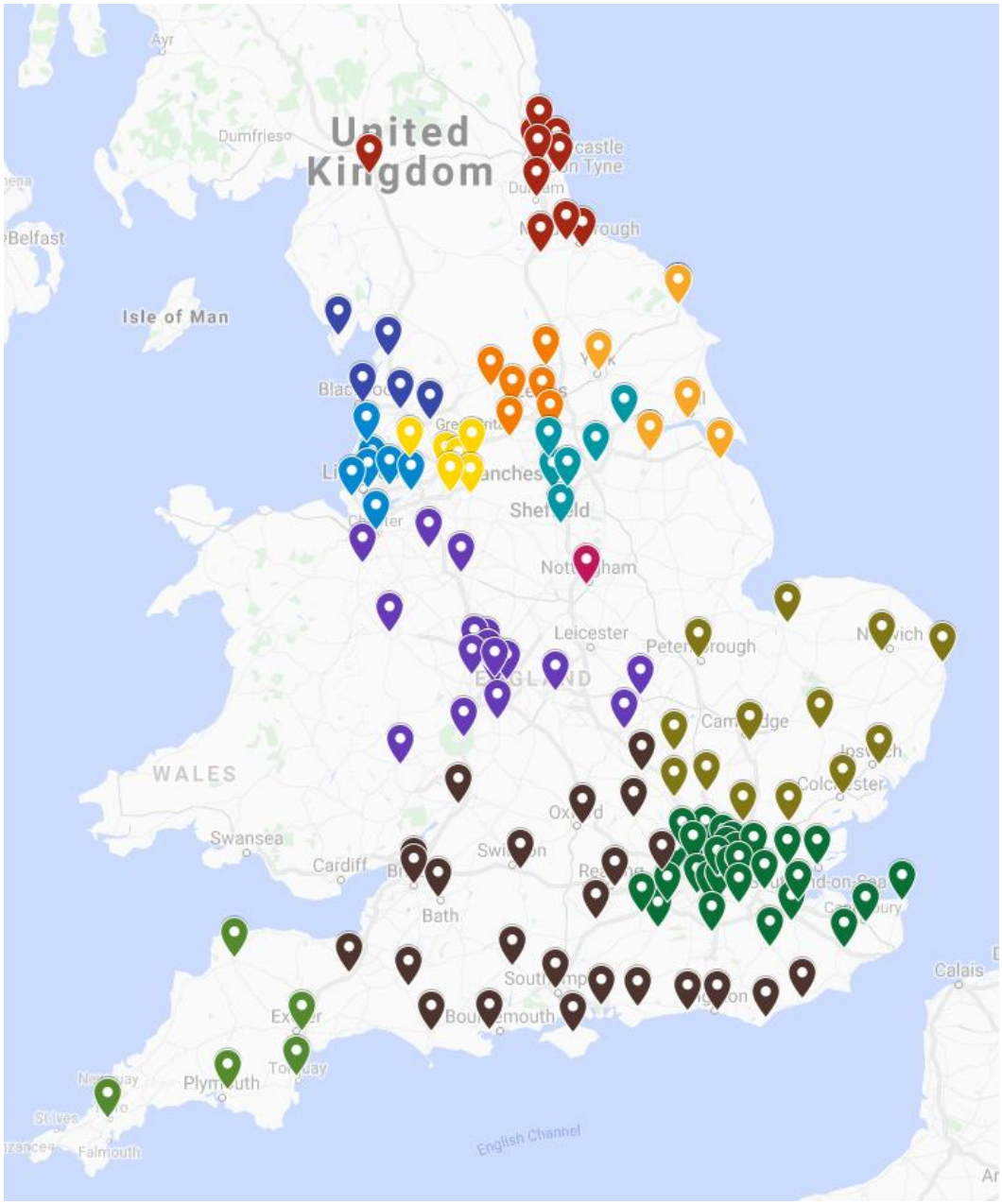


Figure 5.2. Map of Major Trauma Centres and Units in the different Major Trauma Networks

- Cheshire and Mersey Major Trauma Centre Collaborative
- East Midlands Trauma Network
- East of England Trauma Network
- Greater Manchester Trauma Service
- Lancashire Major Trauma Network
- London Major Trauma System
- North Yorkshire and Humberside Major Trauma Network
- Northern Trauma Network
- Peninsula Trauma Network
- South of England Major Trauma System
- South Yorkshire Major Trauma Network
- West Midlands Major Trauma Network
- West Yorkshire Major Trauma Network

The websites of the 120 identified Trusts were searched to retrieve PILs about mTBI. Leaflets relating to mTBI, concussion, minor head injury, head injury, brain injury, and acquired brain injury were retrieved. The full list of identified PILs is included in Appendix 5.2.

PILs were searched for on the websites using centralised PILs repositories in the first instance. If this was not available, or no relevant leaflets could be identified, the search engine of the Trust website was used. If this was in turn unsuccessful, relevant department or services pages were used including: A&E, Neurology, Neurosurgery, Rehabilitation, Trauma and Orthopaedics. If no leaflets could be retrieved through these steps, the search for the Trust was considered unsuccessful. Freedom of information requests were not conducted, as one of the aim of the study was to evaluate accessibility of information for patients who may have not received or lost written hard copies of their PILs.

INCLUSION AND EXCLUSION CRITERIA

Leaflets were included if they:

- Were about TBI / mild head injury / minor head injury
- Concerned with adult populations (inclusive of those targeted to children and adults simultaneously)
- Were produced by NHS Trusts or NHS Foundation Trusts in England

PILs were excluded if they:

- Exclusively concerned paediatric populations
- Presented information about services rather than providing discharge advice
- Focused exclusively on single specific post-injury symptoms (i.e. fatigue, post-traumatic headaches)

DATA EXTRACTION

The selected leaflets were imported into NVivo for data extraction. Initial review of the leaflets suggested that they were typically divided into 3 core sections: red flag symptoms, common post-injury symptoms, and lifestyle advice. Information presented in the leaflets was coded into the relevant category first, followed by more specific text-derived codes. These text-derived codes were then grouped into higher level themes applicable to the wider PILs selection. Figure 5.3 presents an example of this coding process.

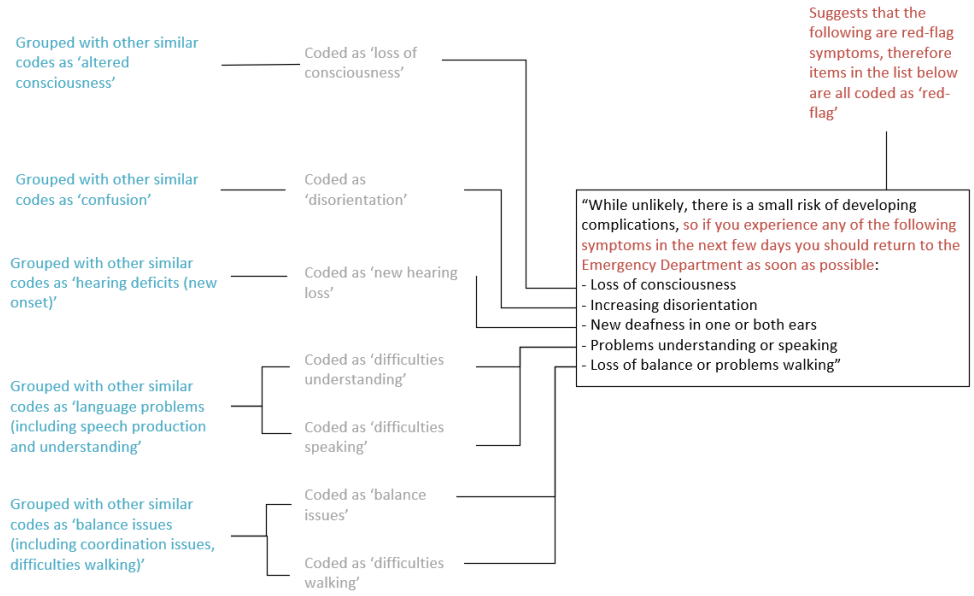


Figure 5.3. Example PIL coding process

Key: Box = sample text section from a PIL; red = relevant category (here 'red flag symptoms'); grey = text-derived codes; blue = higher -level themes

ANALYSIS

The retrieved PILs were analysed on three levels: contents, design, and signposting.

The PIL quality checklist proposed by Sustersic et al.[247] was used as a starting point. The original checklist assesses contents, design and other properties and is presented in Appendix 5.3.

In this study, the checklist was modified: the 'other properties' category was not used as a number of the targeted elements (i.e. "the leaflet was critically read by at least two physicians in the discipline") could not be assessed by this study. Similarly, two of the items in the 'Contents' category were not applicable to this study: "Explains the benefit/risk of a treatment" and "Gives advice on what to do if a dose is missed", since there is no treatment for TBI. The contents of the PILs were also examined thematically in more depth using NVivo qualitative data analysis software.

Items in the Design category pertaining to readability (simple vocabulary, and simple syntax) were assessed using automated readability score tests available online (Flesch reading ease score, Flesch-Kincaid grade level and Simplified Measure of Gobbledygook (SMOG), from http://www.readabilityformulas.com/). To do so, all PILs were converted to MS Word files. This replicated the PILs assessment method used by Mason & Williamson [242]. Flesch scores range from 0 to 100, with higher scores indicating higher readability. Scores between 0 and 30 are considered university graduate level, 30 to 50 are college level, 50 to 60 are US grades

10 to 12 (15 to 18 year olds), 60-70 are US grades 8 to 9 (13 to 15 year olds), 90 to 100 are US grade 5 level (10 to 11 year olds). The Flesch-Kincaid and SMOG scores directly relate to school grades of the American education system. These tests are formula-based and use number of syllables per word and number of words per sentence to evaluate the readability of a text written in English. The readability cut-offs were 60 or over for the Flesch score, and 6 for both the Flesch-Kincaid and SMOG scores, in line with previous studies[242-244].

Finally, an additional category was created to assess signposting to appropriate services and support. This list was built gradually through review of the PILs to identify any relevant care and support services. All identified services were then grouped into four categories (Appendix 5.4).

The resulting quality checklist consisted therefore of 3 domains: contents, design, and signposting. Items of the checklist are presented in Table 5.1.

Table 5.1. Modified checklist items

PIL= Patient Information Leaflet; SMOG=Simplified Measure of Gobbledygook; DVLA=Driver and Vehicle Licensing Agency

Category	Item
Contents	Based on the latest evidence-based medicine
	Declares the objectives of the PILs (writer's intention)
	Explains causes, consequences, the usual course of the condition/disease
	Advice on who, when and where to reconsult
	Advice on "what to do": lifestyle recommendations, surveillance
	Takes into account the patient's needs according to the literature
	Written so that it personally addresses the reader, targeted, culturally appropriate
	Contains easy-to-understand illustrations, diagrams or photographs
	Names the person who wrote the leaflet and their position
	States date of writing and/or last update
	Gives references to sources of the information with dates
	Avoids advertising or pharmaceutical brand names, uses generic names
Design	Favours patient interaction through questions
	Short format
	Layout of information structured, presented in a logical order (paragraphs and titles)
	Not too compact, simple presentation, avoiding colour overload in drawings and boxes
	Readability (Flesch, Flesch-Kincaid, and SMOG scores)
	Standard font (Arial, Times) avoiding small size (10 minimum)
	Use of % to express frequencies, especially for risk perception
	Contains a space to make notes
	Favours patient interaction through questions
Signposting	Charity
	Face-to-face healthcare service
	Online/remote healthcare service
	Other government services (social services, DVLA)

SEARCH RESULTS

A total of 81 PILs were retrieved: 35 concerned paediatric populations only and were excluded. Six concerned both children and adults, and 40 concerned adults only. Of these 46 leaflets, 4 were symptoms specific (2 specific to fatigue and 2 to post-traumatic amnesia), 2 were overviews of specific services (one about a community brain injury rehabilitation service, one about a the early discharge scheme of a brain injury team), 3 addressed specific outcomes outside of the more global TBI context (2 about returning to sports and one about driving), 2 gave an overview of Acquired Brain Injury in general (which included stroke, tumours, and infection), and one focused on a specific subgroup of TBI patients (people with premorbid bleeding disorders). The other 33 PILs gave general advice about mild TBI and were included in the study. The selection process is detailed in Figure 5.4.

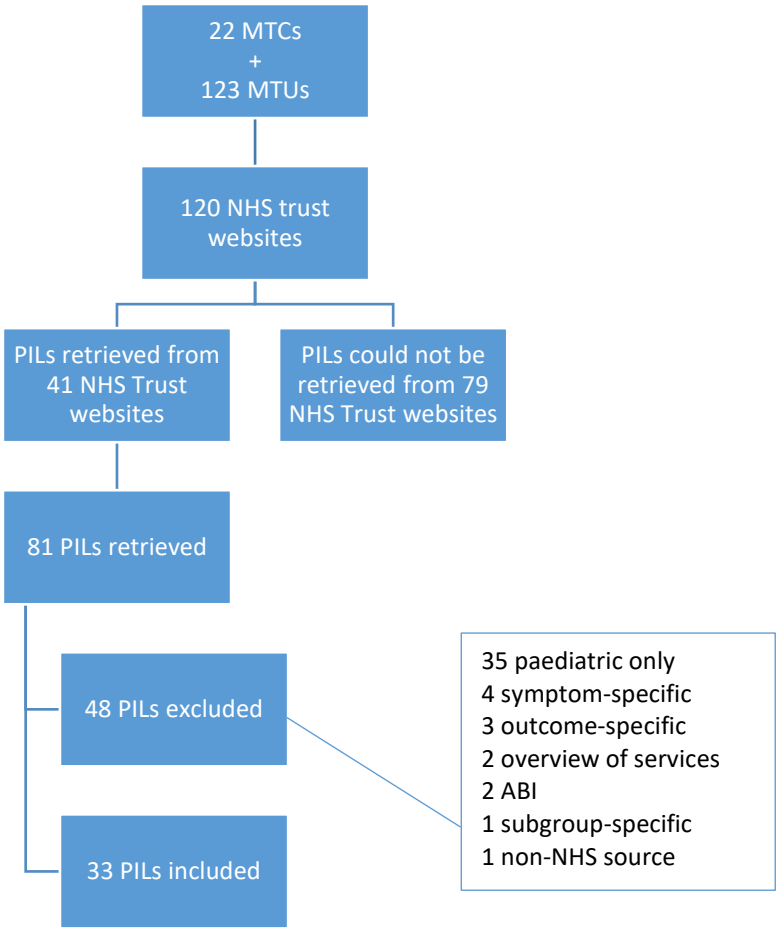


Figure 5.4. Search and selection of Patient Information Leaflets

MTC=Major Trauma Centre; MTU=Major Trauma Unit; PIL=Patient Information Leaflet; ABI=Acquired Brain Injury

The final selection of 33 PILs (Table 5.2) covered 11 MTNs, 20 MTCs (with PILs originating either from an MTC directly or from an affiliated MTU) and 28 NHS Trusts throughout England (Figure 5.5).

Table 5.2. Included Patient Information Leaflets

Leaflet ID	Title	Trust	Affiliated MTC	Major Trauma Network
1	Adult head injury	Cambridge University Hospitals NHS Foundation Trust	Addenbrooke's Hospital Cambridge	East of England Trauma Network
2	Advice for people who have been concussed	Cambridge University Hospitals NHS Foundation Trust	Addenbrooke's Hospital Cambridge	East of England Trauma Network
3	Post-concussion syndrome	South Tees Hospitals NHS Foundation Trust	James Cook University Hospital Middlesborough	Northern Trauma Network
4	Head injury	South Tees Hospitals NHS Foundation Trust	James Cook University Hospital Middlesborough	Northern Trauma Network
5	Advice after a head injury	South Tees Hospitals NHS Foundation Trust	James Cook University Hospital Middlesborough	Northern Trauma Network
6	Head injury advice	Imperial College Healthcare NHS Trust	St Mary's Hospital London	London Major Trauma System
7	Head injury	University Hospital Southampton NHS Foundation Trust	Southampton General Hospital	South of England Major Trauma System
8	Head injury discharge advice	University Hospitals Plymouth NHS Trust	Derriford Hospital Plymouth	Peninsula Trauma Network
9	Head injury adults	Hull University Teaching Hospitals NHS Trust	Hull Royal Infirmary	North Yorkshire and Humberside Major Trauma Network
10	Head injury discharge advice	Sheffield Teaching Hospitals NHS Foundation Trust	Northern General Hospital Sheffield	South Yorkshire Major Trauma Network
11	A patient guide to mild traumatic brain injury	University Hospitals Birmingham NHS Foundation Trust	Queen Elizabeth Hospital Birmingham	West Midlands Major Trauma Network
12	Adult head injury	Brighton and Sussex University Hospitals NHS Trust	Royal Sussex County Hospital Brighton	South of England Major Trauma System
13	Concussion	Brighton and Sussex University Hospitals NHS Trust	Royal Sussex County Hospital Brighton	South of England Major Trauma System
14	Head injury advice - adult	Salford Royal NHS Foundation Trust	Salford Royal Hospital	Greater Manchester Major Trauma Service
15	Head injury advice for patients aged 16 years and over	Mid Essex Hospital Services NHS Trust	Addenbrooke's Hospital Cambridge	East of England Trauma Network
16	Head injury in adults	North Tees and Hartlepool NHS Foundation Trust	James Cook University Hospital Middlesborough	Northern Trauma Network
17	Head injury advice: discharge advice for those aged 12 and over	Buckinghamshire Healthcare NHS Trust	John Radcliffe Hospital Oxford	South of England Major Trauma System
18	Head injury (adults)	Royal Berkshire NHS Foundation Trust	John Radcliffe Hospital Oxford	South of England Major Trauma System

19	Head injury adults	Royal Surrey County Hospital NHS Foundation Trust	St George's Hospital London	London Major Trauma System
20	Head injury in adolescents and young adults	University College London Hospitals NHS Foundation Trust	Royal London Hospital	London Major Trauma System
21	Head injury (adult): aftercare advice	East Kent Hospitals University NHS Foundation Trust	King's College Hospital London	London Major Trauma System
22	Head injury in Adults and older children	North Cumbria University Hospitals NHS Trust	Royal Victoria Infirmary Newcastle	Northern Trauma Network
23	Head injury (adult)	Dorset County Hospital NHS Foundation Trust	Southampton General Hospital	South of England Major Trauma System
24	Head injury: adult	Royal United Hospitals Bath NHS Foundation Trust	Southmead Hospital Bristol	South of England Major Trauma System
25	Head injury advice for adult patients	Yeovil District Hospital NHS Foundation Trust	Southmead Hospital Bristol	South of England Major Trauma System
26	Head injury advice for relatives and friends	Yeovil District Hospital NHS Foundation Trust	Southmead Hospital Bristol	South of England Major Trauma System
27	Head injury advice	University Hospitals Bristol NHS Foundation Trust	Southmead Hospital Bristol	South of England Major Trauma System
28	Head injury in an adult	St Helens and Knowsley Teaching Hospitals NHS Trust	Aintree University Hospital Liverpool	Cheshire and Mersey Major Trauma Centre Collaborative
29	Mild Traumatic Brain Injury and Concussion	Torbay and South Devon NHS Trust	Derriford Hospital Plymouth	Peninsula Trauma Network
30	Discharge advice about head injury (people aged over 12 years)	Northern Devon Healthcare NHS Trust	Derriford Hospital Plymouth	Peninsula Trauma Network
31	Recovering from a Head Injury	Blackpool Teaching Hospitals NHS Foundation Trust	Royal Preston Hospital Lancashire	Lancashire Major Trauma Network
32	Head injuries (adults)	Kettering General Hospital NHS Foundation Trust	University Hospital Coventry	West Midlands Major Trauma Network
33	Adult head injury	Stockport NHS Foundation Trust	Manchester Royal Infirmary	Greater Manchester Major Trauma Service

Figure 5.5. Spread of included PILs throughout England

- Cheshire and Mersey Major Trauma Centre Collaborative
- East of England Trauma Network
- Greater Manchester Trauma Service
- Lancashire Major Trauma Network
- London Major Trauma System
- North Yorkshire and Humberside Major Trauma Network
- Northern Trauma Network
- Peninsula Trauma Network
- South of England Major Trauma System
- South Yorkshire Major Trauma Network
- West Midlands Major Trauma Network

There was some level of regional disparity in the availability of PILs throughout the different MTNs (Table 5.3). No relevant PILs were found in the East Midlands Trauma Network and the West Yorkshire Major Trauma Network. The most PILs were found through Trusts in the South of England Major Trauma System, although this is also one of the largest MTNs, comprising of 24 MTCs/MTUs. The London Major Trauma System is the largest in terms of MTCs/MTUs (N=39), although only 4 PILs were included. Some smaller MTNs had proportionally more relevant PILs: the Peninsula Trauma Network only has 5 MTCs/MTUs, but produced 3 relevant PILs from 3 MTCs/MTUs.

Table 5.3. Number of Patient Information Leaflets by Major Trauma Network

MTC=Major Trauma Centre; MTU=Major Trauma Unit; MTN=Major Trauma Network; PIL=Patient Information Leaflet

Major Trauma Networks	Number of PILS	MTCs/Us from which PIL was retrieved	Total Number of MTCs/Us in MTN
Cheshire and Mersey Major Trauma Centre Collaborative	1	1	7
East Midlands Trauma Network	0	0	1
East of England Trauma Network	3	2	13
Greater Manchester Major Trauma Service	2	2	6
Lancashire Major Trauma Network	1	1	5
London Major Trauma System	4	4	39
North Yorkshire and Humberside Major Trauma Network	1	1	5
Northern Trauma Network	5	3	11
Peninsula Trauma Network	3	3	5
South of England Major Trauma System	10	8	24
South Yorkshire Major Trauma Network	1	1	7
West Midlands Major Trauma Network	2	2	17
West Yorkshire Major Trauma Network	0	0	6

DEPARTMENT SOURCE AND AUTHORS

The majority of the included PILs were produced by A&E departments(N=22) and/or minor injury units (N=3). Two were produced by neuropsychology departments, and one by a trauma and orthopaedics department. Five PILs did not report a specific department source.

Only one PIL included the name of the author and their role. A further 21 PILs indicated either the role of the author or simply a department source. Eleven provided neither.

DATES OF PUBLICATION AND NEXT REVIEW

All PILs indicated a date of publication and or next review. Twenty-seven indicated a publication or issue date as well as a review date. It was unclear whether the review date consistently indicated a date for future review or a date of last review. Assuming the former, 19 were in date and 8 were outdated. Two PILs indicated an issue date alone. Three indicated a review date alone, one of them explicitly labelled “next review”. Finally, one PIL indicated an “expiry” date alone, and was in date.

INFORMATION AND ADVICE

All 33 PILs provided information and advice in line with the latest evidence. Thirty-two provided details about who, when and where to re-consult, as well as lifestyle recommendation and surveillance. Twenty-eight PILs explained causes, consequences, and/or the usual course of TBI.

All PILs were written so that they personally addressed the reader. Thirty-two addressed patient needs in line with those highlighted in the literature (e.g. common symptoms, return to work, driving).

Twenty-four PILs avoided advertising or pharmaceutical brands and used generic names instead. One advertised legal services. This category was not applicable for 8 PILs.

The PILs were generally poor at declaring the objective or writer’s intention, with only 8 doing so. The referencing of information was also poor, with only 5 doing so, and a further 5 prompting readers to contact the authors for references.

Illustrations, diagrams or photographs were only included in 6 PILs and were easy to understand.

In-depth qualitative analysis identified 4 sets of information generally presented in the included PILs: a list of ‘red flag’ symptoms that should prompt A&E re-attendance; a list of common post-injury symptoms; a list of ‘Dos and Don’ts’ lifestyle advice to prevent further injury and promote recovery; and information about risk of both immediate and longer-term complications.

Red flags

Twenty-eight of the 33 PILs listed 'red flag' symptoms. Twenty-five red flag symptoms were identified. Thirteen symptoms were identified in over half of the PILs, including drowsiness, headaches, vomiting, and vision deficits. The other 10 were identified in 5 PILs or less. The full list of identified red flag symptoms and the number of PILs they were identified in is presented in Figure 5.6.

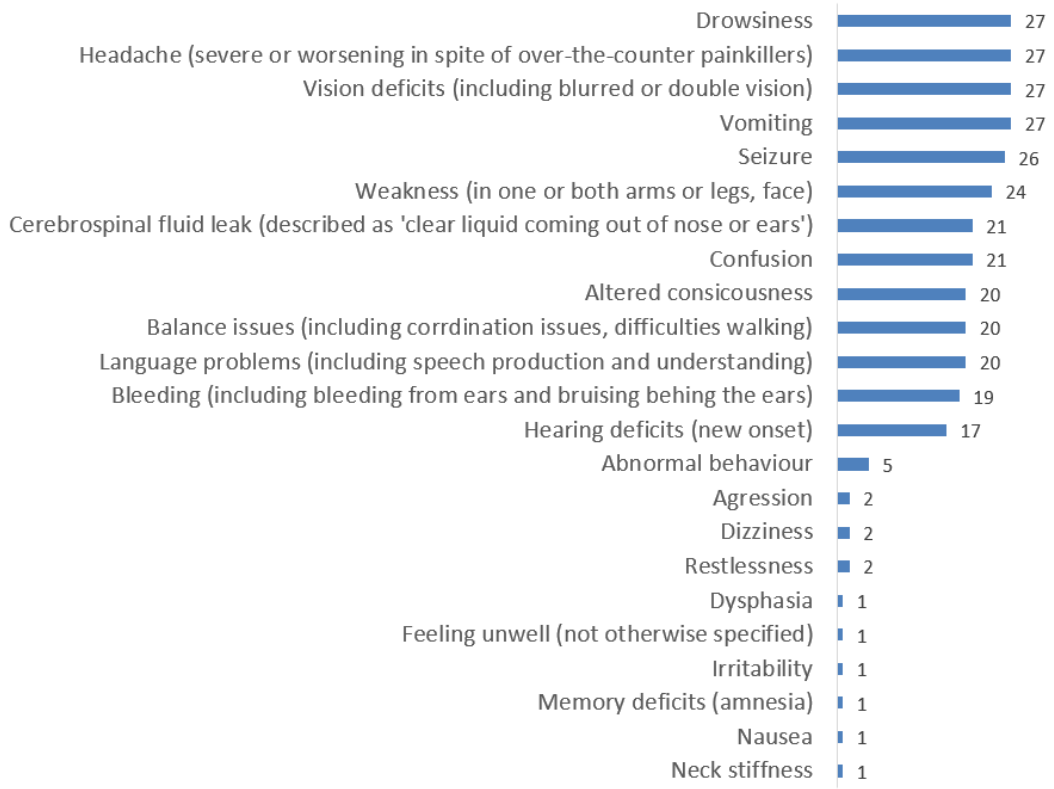


Figure 5.6. Number of Patient Information Leaflets reporting each identified red flag symptom

Common post-injury symptoms

Thirty-one of the 33 PILs listed common post-injury symptoms

Twenty-three common post-injury symptoms were identified. Generally, they were considered to be a normal part of the recovery process, and prompts to seek GP support was only indicated in case the patient was particularly concerned (N=14/33), if the symptoms were severe (N=5/33), worsened (N=3/33) or emerged a few weeks or months following injury (N=1/33). Patients were also advised to seek GP support when the symptoms persisted. The timeframe for this ranged between 5 days and 6 weeks post-injury, although most PILs (N=19/33) proposed a cut-off point of 2 weeks, after which patients were advised to seek GP support.

Thirteen common symptoms were identified in over half the PILs, including fatigue and tiredness, mild and moderate headaches, concentration issues and irritability. The full list of identified common post-injury symptoms and the number of PILs they were identified in is presented in Figure 5.7.

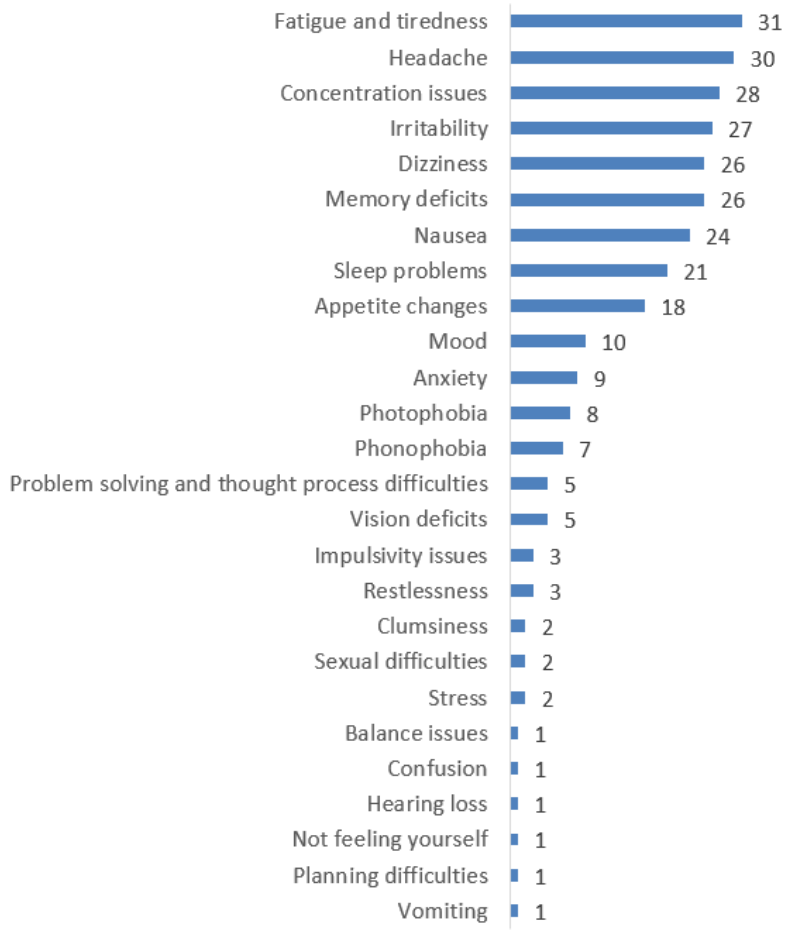


Figure 5.7. Number of Patient Information Leaflets reporting each identified common post-injury symptom

Dos and Don'ts

All PILs presented general advice, most in the form of distinct 'Dos and Don'ts' lists. This lifestyle advice revolved around 6 key themes.

1. Support

Twenty-seven PILs gave recommendations around 'Support', mostly focusing on the post-acute phase (24-48 hours post-discharge). Twenty-five PILs advised patient to not stay home alone in this phase, and to be supervised by a responsible adult capable of identifying red flags highlighted above and take the patient back to A&E as required. Fifteen PILs recommended that patients stay within reach of a telephone in order to call for help if needed. One PIL suggested that patients may find support groups useful.

2. Rest

The second theme was 'Rest'. Twenty-eight PILs highlighted the importance of rest to promote recovery, with particular focus on the post-acute phase. Two PILs also mitigated the advice for patients to "rest as much as [they] need" by highlighting the importance of restoring good sleep hygiene (ID11, ID24) and balancing rest with brain stimulation (ID11) to aid recovery.

3. Stress

'Stress' was also an important theme. Nineteen PILs recommended the avoidance of stressful situations. More specifically, 5 PILs discussed physical rest and recommended limiting strenuous activities to prevent physical exertion. Six PILs referred to cognitive stress suggesting patients avoid prolonged concentration (e.g. reading) and extended screen time (e.g. watching television, browsing the internet).

4. Healthy Diet

Thirty-two PILs mentioned 'Diet', particularly advising patients to avoid alcohol (N=32) and recreational drugs (N=15). Five PILs advised patients to drink plenty of water. Three PILs recommended patients eat light meals that rich in fruit and vegetable, and limit excess sugar.

5. Medication

Thirty-one PILs discussed 'Medication'. Most advised against the use of sleeping tablets, sedatives or tranquilisers unless prescribed by a doctor (N=24), and advised patients to use over-the-counter analgesics (e.g. paracetamol, ibuprofen) to relieve headaches. Three PILs advised patients not to use aspirin, and 4 recommended patients continue taking any medications prescribed for co-morbid conditions.

6. Return to activity

'Return to activity' was an important theme in 31 PILs. Twenty-six discussed return to work specifically, advising patients to take time off work until post-injury symptoms resolved. They also advised to return to work gradually. Similarly, patients were advised to refrain from sports (N=27), and particularly contact sports (N=23), for 3 weeks following injury, as well as follow a gradual return process. Patients were also advised to refrain from driving in the first few days after injury, and to seek medical advice before returning to driving or operating heavy machinery.

Risk of complications and recovery time

Risk of complications were explicitly mentioned in 23 PILs and broadly divided into immediate risk related to red flag symptoms discussed above, and risk of experiencing persisting symptoms. All 18 PILs addressing risk of immediate complications reported that these are very unlikely. Seventeen PILs addressed minor symptoms that may appear and/or persist after injury. They generally highlighted that these are common, but typically disappear within a few days to a couple of weeks. 9 PILs highlighted that these symptoms can sometimes persist for longer.

DESIGN

The PILs generally met 4 of 8 design criteria of the modified checklist.

All 33 PILs were found to use an appropriate font type and size, although they were fairly difficult to read. Descriptive statistics for the different readability tests are presented in Table 5.4.

Table 5.4. Readability scores

SMOG=Simplified Measure of Gobbledygook

	Flesch	Flesch-Kincaid	SMOG
Mean (standard deviation)	59.8 (6.2)	8.1 (1.0)	8.2 (0.8)
Median (range)	59.4 (41.3-70.5)	7.8 (6.3-10.7)	8.1 (7.1-10.5)

The average word count was 701.4 words long, although the length of PILs varied substantially throughout the sample (sd=413.5), the median length was 628 words, and the range was 276 to 2607. In terms of semantics, the majority (N=29) used the term "head injury", 4 referred to "concussion" and two "mild traumatic brain injury". Some PILs used a combination of those terms throughout.

Thirty-two PILS used a structured layout of information (e.g. paragraph and titles presented in a logical order), and 29 were not too compact and avoided colour overload.

However the PILs performed poorly in terms of favouring patient interactions through questions, with only 4 doing so; containing a space to make notes (N=4, with a further 10 including enough blank space to allow for notes while not explicitly designated it as such); and using percentage to express frequencies for risk perception (N=2).

SIGNPOSTING

Signposting was divided into 4 categories. The first category was “face-to-face healthcare services” and included GP, Head Injury Nurse, A&E and Minor Injuries clinic. The second was “remote healthcare services” and included the NHS website, 111, Patient Advice and Liaison Services, and the Patient Info website (which is certified to meet NHS England’s information standards). The third was “charity organisations” and included Headway, UKABIF, the Brain and Spine Foundation, the Brain and Spinal Injury Centre, and Citizens Advice). The fourth and final category was “other government services” and included social services and the Driver and Vehicle Licensing Agency (DVLA).

All 33 PILs signposted to face-to-face healthcare services, including 30 to GPs, 27 to emergency services, 4 to walk-in centres, and 3 to head injury nurses. Nineteen PILs signposted to remote healthcare services, mainly to the 111 helpline (N=17). Seven directed patients to the NHS website, 4 to the Patient Info website and 2 to PALS. One further PIL signposted to 111, but as this was part of the standard leaflet template rather than specifically written as part of the population-specific content. Similarly, 5 PILs indirectly signposted to PALS. Thirteen PILs signposted to charities, mostly Headway (N=13). Two PILs signposted to further government support services, including the DVLA (N=2) and social services (N=1).

MODEL PATIENT INFORMATION LEAFLET

A model leaflet was created combining information extracted from the PILs included in this study, and following the checklist used for quality check. This leaflet was also assessed for readability and holds a Flesch score of 65.6, a Flesch-Kincaid score of 6.5 and a SMOG score of 6.7. This suggests that this composite leaflet is easier to read than the included PILs.

Mild Traumatic Brain Injury

(also called 'Head Injury' or 'Concussion')

You have a mild Traumatic Brain Injury.

The doctor who examined you at A&E is happy for you to go home as your injury is only mild (minor).

It is unlikely that you will have serious complications, but if you do, you must go back to A&E immediately.

It may take a few weeks for you to feel better.

This leaflet contains information about serious symptoms to watch out for, common symptoms that should go away on their own, and advice about what to do to help your recovery.

Do I need to go back to A&E? (Serious complications)

Serious complications after a mild Traumatic Brain Injury are rare but are dangerous.

If you experience any of the following symptoms, go to your local Emergency Department or call 999:

- Severe headache (that does not go away with paracetamol or ibuprofen)
- Any vomiting (being sick)
- Any fits (seizure)
- Clear fluid coming out of one or both of ears or nose
- Bleeding from or bruising behind one or both ears
- Problems with your eyesight (blurred or double vision)
- New deafness in one or both ears
- Any weakness in one or both arms or legs
- Problems speaking or understanding
- Excessive drowsiness (feeling very sleepy) when you would be normally wide awake
- Loss of consciousness (passing out)
- Confusion (not knowing where you are, getting things muddled up)
- Any loss of balance or problems walking

Your local A&E department
[insert A&E contact information]

If you need an ambulance

Call 999

If you are not sure if this is an emergency

Call 111

Mild Traumatic Brain Injury

(also called 'Head Injury' or 'Concussion')

What should I expect after a Traumatic Brain Injury? (Common symptoms after mTBI)

It is normal to experience some symptoms after a traumatic brain injury. These are common, and should disappear on their own within the next 2 weeks.

- Mild headaches (that get better with paracetamol or ibuprofen)
- Fatigue/tiredness
- Feeling restless
- Sleep problems (sleeping more or less than usual)
- Difficulties concentrating
- Difficulties thinking clearly
- Being forgetful (memory problems)
- Nausea (without vomiting)
- Feeling dizzy
- Sensitivity to light and noise
- Irritability (short temper)
- Impulsivity
- Feeling depressed, tearful, stressed, or anxious
- Low appetite
- Sexual difficulties

Should I see my GP about my symptoms?

The hospital will have sent a letter to your GP explaining that you have had a Traumatic Brain Injury. It is normal to have symptoms for a couple of weeks after a traumatic brain injury. These symptoms should go away on their own.

You should see your GP if:

- You are very concerned about your symptoms,
- Your symptoms get worse over time, or
- They have not disappeared after 2 weeks

Your GP
[insert patient's GP contact information]

Mild Traumatic Brain Injury

(also called 'Head Injury' or 'Concussion')

What can I do to get better?

Get support

- Stay within reach of a telephone so you can call for help
- Have a responsible adult stay with you in the first 48 hours after A&E

Rest

- Get plenty of rest
- Try to keep a normal sleep schedule (sleep at night, awake and resting during the day)
- Limit the time you spend looking at screens (e.g. TV, phone, tablet) or reading

Stress

- Avoid stressful situations

Healthy diet

- Eat light meals
- Drink plenty of water
- Avoid alcohol and drugs

Medication

- Take paracetamol or ibuprofen if you have a headache
- Continue taking your normal medication
- Do not take tranquilisers, sedatives or sleeping tablets unless a doctor has prescribed them

Return to activity

- Do not return to work or school until your symptoms have resolved
- Do not play contact sports for 3 weeks after your injury and visit your GP before you start playing again
- Do not drive or operate machinery in the first few days after your injury

Where can I get more information and support?

You can find more information about brain injury on:

- the NHS website: nhs.uk/conditions/minor-head-injury
- the Headway website: headway.org.uk
- the Brain Injury Rehabilitation Trust website: thedtgroup.org/brain-injury

In your area
[Add information about any local support
(i.e. Headway support group meetings, contact number for local branch, etc.)]

Mild Traumatic Brain Injury

(also called 'Head Injury' or 'Concussion')

Specific advice

[space for clinician to write any specific advice]

Notes

[space for patient to take notes]

DISCUSSION

AVAILABILITY AND ACCESSIBILITY OF WRITTEN INFORMATION

Mild TBI is common and bears risks of serious immediate complications. Although rare, the risk for such complications warrants that patients discharged from A&E receive appropriate information about symptoms to watch out for as well as clear instructions about the course of action to take in such situations. It is reasonable to assume that all patients will have received written information upon discharge from A&E, as it is prescribed by clinical

guidelines [26]. However, it is possible that patients and their families may misplace written forms, and thus it seems critical that this same information be available, and easily accessible, online.

The present study shows that this is not the case, with more than half of the NHS Trust websites explored failing to include centralised PILs repositories. Of the websites where information was available, it was not always clearly signposted and necessitated searches through automated search engines or manual navigation through multiple pages. Although relevant PILs can be found, it may be difficult for patients and their relatives to access them. This lack of availability of PILs online is not limited to TBI [242].

There was some level of regional disparity in the availability of relevant PILs online. In place of Trust-specific PILs, some Trust websites signposted to national online resources (e.g. Patient Info, NHS website), which are not regionally anchored, and therefore lack contact information for patients' local services, of which provision is variable. In addition, these online resources tend to list mild TBI under a variety of terms, such as 'head injury' or 'concussion', which patients might not be aware of. The semantic variability was also present throughout the PILs included in this study, recalling the terminology debates of the field (Chapter 1).

Availability of information does not necessarily mean that it is accessible to patients. Indeed, studies have highlighted that often patients do not understand the information given to them by doctors. This is true both for verbal and written information, and is not solely a factor of fading memory of instructions after discharge [232,248]. As identified with the PILs in this study, readability of written information distributed to patients is often above the recommended reading age [242-244].

The availability and accessibility of written information online should not be a substitute for appropriate verbal instruction provided at discharge [233(item 1.5.12, p.15),26(items 1.9.7 and 1.9.8, p.38)]. These modalities are complementary, and their combination may enhance understanding of discharge instructions [249].

TBI INFORMATION AND ADVICE

Although the advice provided in PILs falls along 4 broad categories (red flags, common post-injury symptoms, dos and don'ts, and information about recovery time and risk of complications), it was not always consistent, and at times contradictory, across Trusts. In this study, 6 symptoms (of 43) were included in both the red flag and common symptoms category, which warrant contradictory courses of action regarding A&E attendance. Similarly, any vomiting was generally considered a red flag symptom, but some PILs considered that it only warranted A&E attendance if it occurred more than twice.

This lack of consistency concerned only a small number of symptoms and few PILs. No contradictory information found within one single PIL. However, this raises a question about the reliability of advice provided in PILs. Such inconsistencies between PILs has previously been highlighted[250].

Most PILs highlighted that post-injury symptoms are common in the few weeks following TBI, but few discussed the relatively high risk of experiencing more prolonged symptoms. P-TBI-S is not rare however, as affects around 30% of patients. It would seem appropriate for this information to be included in PILs to ensure that risk perception is accurate.

In spite of this, advice was generally given to seek support from their GP if patients experienced lasting symptoms. This is consistent with the central gatekeeping role GPs play within the NHS. Indeed, GPs have the advantage over specialists to know patients in a context, over time, and therefore to forge a holistic understanding of a person [251]. As such, in their assessment of people with P-TBI-S, they may be able to appraise symptoms that stand-out compared to the patients' baseline. Consequently, their referral decisions will be more individually tailored.

Nevertheless, this approach to further management of patients with P-TBI-S assumes that all GPs are not only expertly knowledgeable about mTBI and its heterogeneous consequences (Chapter 1), but that they are aware of and have access to appropriate community therapies and medical support services [159]. The added difficulty for GPs in working with these patients is the lack of specific rehabilitation guidelines, leaving them to rely largely on clinical judgement, and therefore TBI expertise, to make any referral decisions.

Only 13 PILs signposted to charities. This is a missed opportunity for further patient education. For example, the Headway website includes a large information library, including general information about brain injury, and specific post-TBI symptoms. It also includes sections about employment and education, family issues and relationships, legal issues, and practical issues following brain injury. Charities also represent an important bridge between clinical services and a successful return to community life for a patient population for whom there is a lack of defined care pathway in the community.

An important proportion of patients discharged from A&E with uncomplicated mTBI go on to experience P-TBI-S. As such, specific referral at A&E discharge to specialist outpatient brain injury services for follow-up, or opportunities for patients to self-refer to such services, may be more appropriate than the GP referral route.

The model PIL, combining the information extracted from the selected PILs presents two main advantages: firstly, it constitutes a unified message that could be used across Trusts,

therefore reducing duplication of work in producing and updating leaflets. The approach of using a generic leaflet seems appropriate, as none of the PILs analysed in this study provided Trust or region-specific advice about services or otherwise. The proposed model leaflet allows for customisation should specific services be available in any given Trust. In addition, the model PIL signposts to other national resources, such as the extensive Headway library, where patients and their families can find more detailed advice.

This study highlighted a significant lack of transparency regarding authorship and sources of information. In an important proportion of cases, determining whether the information was in date was difficult. This was due to the lack of consistency about reporting of issue and review dates. However, the information provided in the PILs that were obviously outdated was not qualitatively different from this provided in the other PILs. This lack of transparency about authorship, sources of information, and review process seem at odds with the ethos of MTNs, which were created to standardize care through implementation of best practices.

LIMITATIONS

This study presents a number of limitations, both methodological and theoretical.

Methodological limitations

No comprehensive list of MTCs and MTUs could be retrieved. As such, the list used in this study was created manually from information available through the NHS website and MTN-specific websites. The latter do not follow standardised formats and do not always list affiliated MTCs and MTUs. As a result, it is possible that some MTCs and MTUs were missed from the list. In particular, no information could be found regarding a potential East Midlands Trauma Network, although Queen's Medical Centre Nottingham was identified as an MTC, but could not be linked to any surrounding MTN. As an alternative, the comprehensive list of acute trusts could have been used, although it would have not allowed for comparison of PILs between regionally anchored networks. In addition, the use of MTNs as a basis for this work has highlighted the lack of centralised information about the organisation of these networks, which add to the complexity of already opaque care systems which patients with mTBI need to navigate.

The use of automated readability scores presents limitations [252]. They often score materials as more difficult to read than users would, in part because they do not account for semantics [253]. Many medical words are polysyllabic, which would lead to greater difficulty according to formulas used in readability test. While such complex medical terms were used in the PILs reviewed in this study, they were often accompanied by lay language definitions, which the tests would have not taken into account. In addition, formatting choices (e.g.

underlining words, paragraph heading, bold font, etc) are not taken into account by automated tests, when they can enhance the readers' experience and increase actual readability. As such the readability scores generated from automated formulae should not be used in isolation to determine the quality of a PIL [242].

Theoretical limitations

Patients with P-TBI-S are at risk of falling through the gaps of care. Better information and signposting following A&E discharge may be an important measure to limit this. However, many patients with mTBI do not attend A&E following their injury, as such, they may not have access to this information in the first place [19,77].

Beyond availability and accessibility issues discussed previously, it is possible that patients with P-TBI-S do not reach out to support services because of the cognitive deficits brought about by their injury. Indeed, such cognitive difficulties may prevent patients from identifying issues that would warrant further support. Patients may fail to attribute difficulties to their brain injury, they may struggle to understand the information given to them, and may find navigating complex care and support services systems difficult. As such, it is important that not only patients themselves, but those around them (i.e. relatives and friends) are knowledgeable about the potential consequences of TBI, and are aware of the course of action to take. The National Institute for Health and Care Excellence guideline recommends that people discharged home from A&E following TBI should be supervised by a responsible adult [26(item 1.9.5, p.60)].

IMPLICATIONS FOR PRACTICE AND FUTURE RESEARCH

This study highlighted disparities in the availability of information across MTNs in England. In order to maximize chances of patients accessing NHS certified information, it seems crucial that they are provided with up-to-date, well-structured PILs, presenting relevant information regarding TBI and local services, at discharge from A&E. It is also important that this same information is easily accessible, to them and their relatives, online.

The organisation of the Major Trauma system is complex and fluid. It is unlikely that patients are aware of the links between regional MTCs and MTUs, and therefore look for information on these affiliated Trust websites when PILs are not available on their local Trust website.

It is also likely that patients looking for information online will initially fall on the national NHS website, rather than their local Trust website. It would be beneficial for region specific service information to be available alongside general TBI information and advice on these national pages, by using location services data or asking visitors for their postcode within the webpage.

The lack of defined rehabilitation care pathways for this patient population increases the role of patients as advocates for their own health as the onus is largely on them to manage their symptoms and seek further support as needed. As such, it is pivotal that the information distributed to them in healthcare settings sets the foundations for successful self-management and is easily accessible.

CONCLUSION

This chapter set out to examine the information leaflets distributed to people discharged from A&E following a mild TBI and address 2 questions:

1. What is the nature and extent of patient education about P-TBI-S at discharge from acute care?
2. What advice is given about access to further support for P-TBI-S?

This study suggests that the availability and accessibility of PILs online was limited throughout England. The information presented in these leaflets typically included lists of symptoms that should prompt re-attendance to emergency services, and symptoms common after mTBI. In addition, most leaflets included lifestyle advice to limit symptoms and promote recovery. However, this advice was largely non-specific. In addition, signposting to services and resources other than A&E departments and GPs was limited and inconsistent between the different PILs evaluated.

The results from this study suggest that although patients are responsible for seeking further support if post-injury symptoms persist, little information is available for them to do so.

Although, nationally, patient information about P-TBI-S and management of P-TBI-S is limited, questions pertaining to the existence of local care pathways still need to be explored. In particular, the organisation of services and transitions between those services for people with P-TBI-S even in the absence of defined care pathways must be explored. This will allow for the identification of points at which patients with P-TBI-S may fall through the gaps of care. Finally, exploration of local provision should highlight any current perceived shortcomings and uncover areas for improvement in the care of this patient population. A detailed exploration of care for this patient group in Coventry and South Warwickshire is presented in Chapter 6.

CHAPTER 6 – HEALTHCARE AND SUPPORT PROFESSIONALS INTERVIEWS

The previous chapter explored the accessibility, availability and contents of patient information leaflets (PILs) distributed to patients at the point of discharge from A&E departments across England following mild Traumatic Brain Injury (TBI). The information, or lack thereof, available in these leaflets confirmed findings from the review of the literature (Chapter 3) which indicated that no systematic follow up of this patient group is recommended. The advice presented in the PILs generally signposted patients either back to emergency services or to their GP in case of persisting symptoms. It remains unclear however how people are managed when they seek help following the emergence of P-TBI-S, whether at A&E departments, GP surgeries, or elsewhere in the care system.

In this chapter, the care system for this patient group in Coventry and South Warwickshire will be explored in order to further the understanding of current practice in the management those patients. There will be a particular focus on transition between different services across the acute-chronic care continuum, as well as an exploration of factors impacting the decisions of healthcare and support professionals in managing these patients.

Figure 6.1 highlights the place of this study within the broader structure of this thesis.

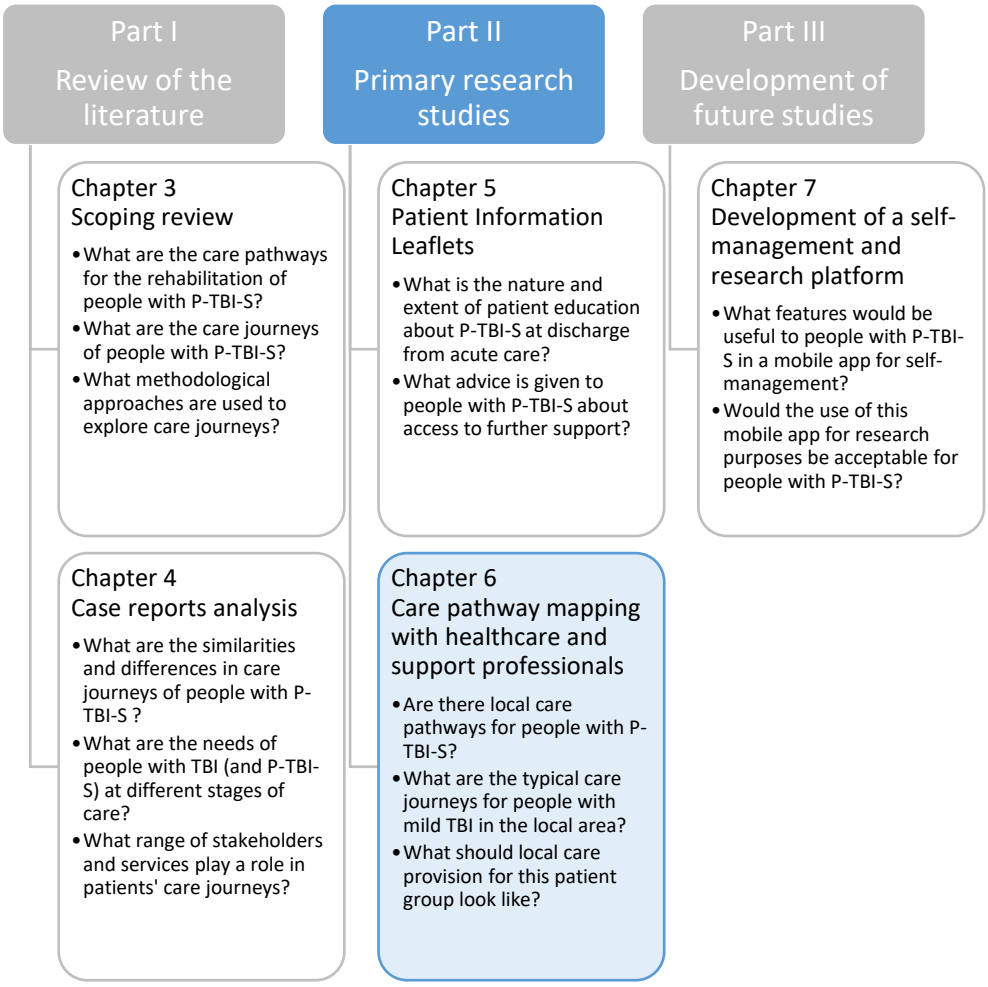


Figure 6.1. Chapter 6 within thesis structure

BACKGROUND

Care pathways for people experiencing persisting symptoms following a TBI are largely undefined. The scoping review (Chapter 3) showed that few guidelines overseeing the rehabilitation of this patient group exist, and that the variability of both patients and their injuries render the production of one-size-fits-all models of care difficult. Exploration of the care journeys of people with Post Traumatic Brain Injury Syndrome (P-TBI-S) (Chapter 4) showed similarities in the services and stakeholders encountered in community settings, but patterns of access were complex. The lack of defined pathways represents a significant barrier to care as it is likely that offer of services varies in different areas of the country. Further barriers were highlighted through the evaluation of information distributed to patients with head injury at discharge from A&E departments (Chapter 5). There is a central role for patients in self-managing any lasting consequences of their injury. This study also showed a central role for GPs in the care of people with P-TBI-S.

The work presented in previous chapters has highlighted a number of features of P-TBI-S illustrating the need for robust care pathways. In addition, they uncovered components necessary to the development of such pathways, including access to better information and key stakeholders. However, this work showed substantial silos of care, which may complicate patients' journey to recovery.

Studies in the reviewed literature have explored the referral routes in and out of specific rehabilitation settings, but they rarely provided an overview of the broader care journeys. Methodological challenges facing research with this heterogeneous patient population have led to focus on specific and more homogeneous subgroups, and/or narrow care settings. As such, these approaches do not allow for the documentation of variation in care and care seeking patterns of the wider TBI population.

These challenges highlight a need for an alternative research approach, using a systematic methodology to model procedural knowledge from healthcare and support professionals to understand processes carried out in practice. The flow of patients between different services is guided by clinical decision-making. A thorough understanding of accurate processes at various interfaces of the patients' journeys can then reflect what is needed for the development of care pathways.

RESEARCH OBJECTIVES

The aim of this study was to explore the services in Coventry and South Warwickshire that are available for the rehabilitation of people with P-TBI-S, highlight any factors impacting care journeys and produce a blueprint of the care pathways and journeys of people with P-TBI-S. Three research questions guided this study:

1. Are there local pathways for people with P-TBI-S?
2. What are the typical care journeys for people with mild TBI in the local area?
3. What should local care provision for this patient group look like?

METHODOLOGY

A qualitative approach was used in this study in order to collect rich data enabling the production of a large-scope blueprint of care journeys for people with P-TBI-S in Coventry and South Warwickshire. This was envisioned as the initial stage of a broader project which will build upon these initial findings to plug quantitative patient data into the blueprint. Ultimately, this will enable the exploration of statistical pathway variation analysis and the proposal of care pathways for this patient group. Contextualisation of this study within a broader research project, and rationale for the methodological approach chosen for this work are detailed in Chapter 2. Semi-structured interviews were used in this study to i) map

clinicians perspectives on care pathways and journeys using Role-Activity Diagram modelling, and ii) explore clinicians views of current care for people with P-TBI-S using Thematic Analysis.

ROLE-ACTIVITY DIAGRAM MODELLING

Workflow modelling is an important step towards the optimisation of service delivery in healthcare settings. This process is often challenging because of the complexity of care processes, which encompass information transfer, resource use, and interactions between services and staff. Moreover, care must be patient-specific, and thus patient flows will be dependent on patient outcomes at different stages of care. Workflow modelling allows for a deeper understanding of the factors impacting care journeys. This chapter utilises a problem structuring approach that is commonly used in soft operations research, and which relies on modelling qualitative information derived from the interviews of key decision-makers [254-256]. This approach aims to provide a structure for mapping complex information that contains high levels of uncertainty: this is the case for this patient group, as little systematic information exits on care pathways for people with TBI outside of the acute care context. Soft operations research techniques allow mapping of individual experts' procedural knowledge from their point of view thus generating individual conceptual maps involving care-related decision-making and processes of care. These individualised maps are then merged to develop an in-depth framework of pathways to care as they occur in practice.

Role-Activity Diagram (RAD) modelling is a type of workflow modelling initially developed to model collaborative processes in business contexts [257,258]. As care for people with P-TBI-S requires multidisciplinary collaboration, this approach was used to map care processes. RAD modelling enables the visualisation of processes that are otherwise hidden or ill-defined, such as bottlenecks and resource-based decision-making, and that can result in ineffective and/or inefficient care delivery processes. The RAD development process in this project comprises 7 stages (Figure 6.2).

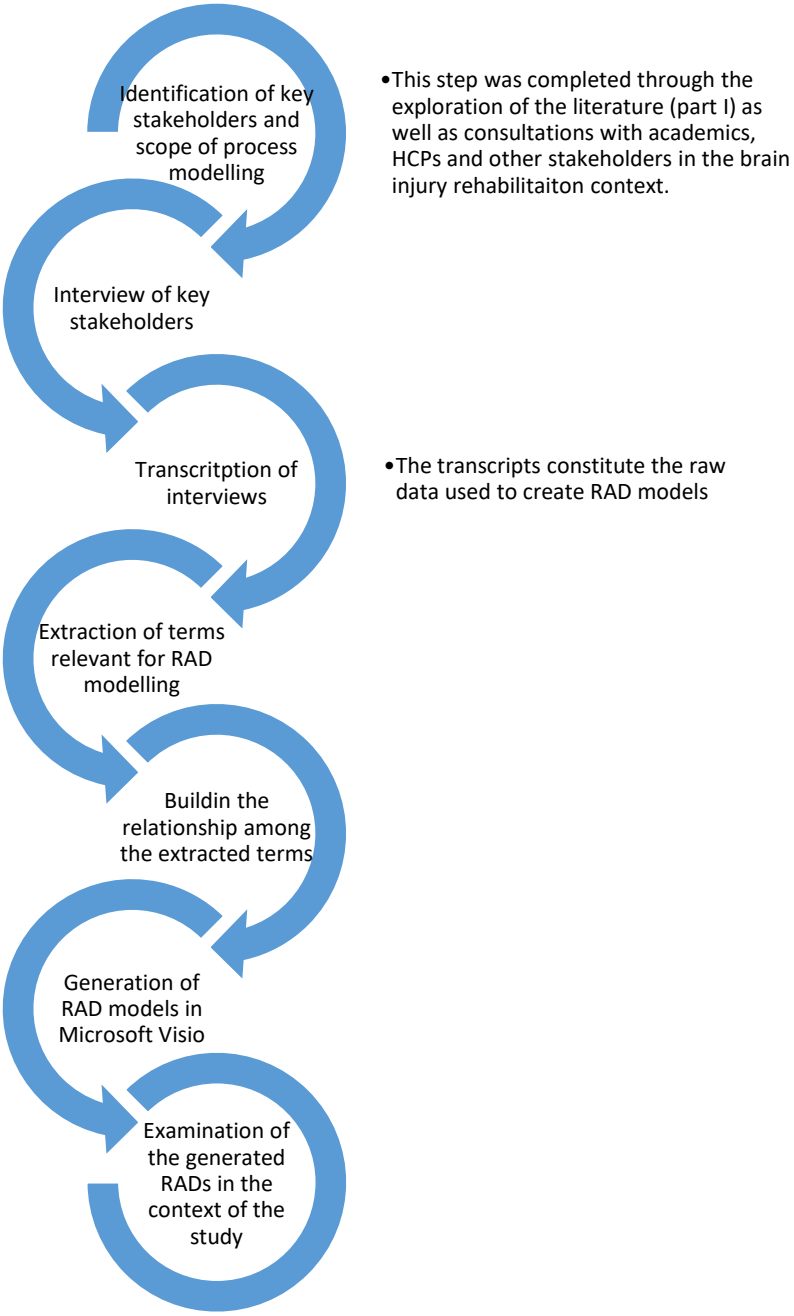


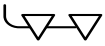
Figure 6.2. RAD modelling process

RAD=Role Activity Diagram; HCP= Health Care Professional

Pathway modelling using RAD presents a number of advantages. The first lies in the nature of its output as a visual representation of pathways. The generation of a detailed pathway diagram can clearly highlight points in care that are likely to lead to poor patient management, or cause delays. For example, a cascading decision-making process increases chances for errors in patient management, particularly if an error is made early on in the cascade. The second advantage of RAD modelling lies in its ability to allow for the

representation of multiple variables simultaneously. Not only does RAD allow for the recording of roles and actions, but also for resources and nature of processes, such as case refinement, encapsulated process, loop, or replication. The third advantage of RAD is that allows for the modelling of parallel care routes. With a population as heterogeneous as the TBI population, it is expected that the care routes are highly variable. The aim of the RAD methodology here is to identify points of divergence and convergence between these different routes and highlight the causes of such variation. RAD models are also compatible with pathway variation analysis that have been used to optimise healthcare systems [259]. The fourth advantage of RAD is that it can generate pathway blueprints against which larger patient data sets can be compared. The development of RAD maps can enable the visualisation of high variation areas, as well as points of care at which patients may fall through gaps and from which they may struggle in accessing the care they need. The RAD concepts used in this study are presented in Table 6.1.

Table 6.1. RAD concepts

RAD concept	Capability type	General description	Examples in TBI care	Graphical notations
Setting	Other	A setting encompasses processes carried out by one or multiple stakeholders in a specific context.	*A&E, neurosciences ward, TBI clinic*	
Activity	Sequential or parallel process	An activity is a specific unit of work.	*Request transfer to neurosciences ward*	
Outreaching activity	Sequential or parallel process	Involvement of a stakeholder who is not normally part of the setting	*GP contacting rehabilitation consultant about patient's prescription*	
Case refinement	Sequential Process	The case refinement is used to represent decision question and possible outcomes.	Decision question: *Does the patient require further rehabilitation*? Outcome: *Yes*, or *No*.	
Trigger	Sequential Process	Trigger is an event that starts the activity thread.	*TBI occurs*	
State	State transitions	A state describes what is true either before or after some actions (actions can encompass activities, interactions, and encapsulated processes).	*Patient attends TBI clinic*	
Loop	Repetition	The loop symbol allows a part of a process to be repeated. The iteration starts at the end of an activity and goes back to a prior activity.	*Repeated evaluation of referral options*	
Encapsulated process	Hierarchy	The encapsulated process allows us to represent complex sub-processes as a separate diagram and indicating it as a symbol in the main diagram	*Perform neuropsychology assessment*	
Other work	Other	It represents the other work that does not relate to the main process being documented or elements of the process that are ill-defined.	*Wait for rehabilitation bed*	

The nature of this approach de facto limits the potential for large sample sizes in comparison to quantitative approaches. In their work, Shukla et al. [259] successfully developed acute stroke care pathway maps using data from Health Care Professionals' (HCPs) interviews. The present study replicates this method in a TBI context.

Preliminary work

As TBI care spans a number of disciplines across different levels of care (from acute to community-based), preliminary work was undertaken to test the viability of using RAD to map processes of this scope, and identify stakeholder of interests for interview.

The mapping method was tested through preliminary meetings with a group of occupational therapists, and a neuropsychologist. Blueprints of care pathways were created using information available in the literature and refined following the meetings (Appendix 6.1). This initial process suggested that there is no unique pathway of care for people with TBI, and that interviews were a viable way to map specific care journeys in detail for this patient population.

THEMATIC ANALYSIS

Thematic Analysis (TA) is a qualitative analysis method used to identify, analyse and report themes within data. It differs from other types of qualitative analysis such as grounded theory or interpretative phenomenological analysis in that it is not confined to preconceived theory about what should be found within the data, but rather derive themes from the data itself. In the context of this study, TA was used as a complementary technique to the RAD modelling of care pathways. In this respect, the aim of this analysis was to identify elements informing care and care pathways beyond those actively sought through for RAD modelling purposes (i.e. resources used, decision-making processes, interaction between services). TA comprises 6 key steps [260]:

Table 6.2. Thematic Analysis steps

(Adapted from Braun & Clarke, 2006 [260])

1 Familiarisation with data
2 Generation of initial codes
3 Search for themes
4 Review of themes
5 Definition and naming of themes
6 Writing up of report

METHODS

STUDY SITES

Three study sites were selected for this study and represent a mix of urban and rural areas of the West Midlands: the University Hospitals Coventry and Warwickshire NHS Trust, the South Warwickshire NHS Foundation Trust, and the NHS Coventry and Rugby Clinical Commissioning Group (CCG).

SAMPLING AND RECRUITMENT

HCP roles typically involved in the care of people with TBI were identified through the scoping review (Chapter 3) and preliminary meetings with stakeholders in the local area. A list of HCP roles of interest for this study, as well as target numbers of interviewees, were generated and is presented in Table 6.3. The target number was determined through conversation with academic and clinical colleagues, with the aim of ensuring stakeholders from all services potentially accessed by people with P-TBI-S were represented.

Table 6.3. HCP roles of interest

HCP=Health Care Professional

HCP role	Acute Care in-patient	Rehabilitation in-patient	Community-based out-patient
Case Manager / Trauma Coordinator / Key worker	1	1	1
Discharge team	1	1	
General Practitioner			2
Neurosurgeon	1		
Nurse / community matron	1	1	1
Occupational Therapist		1	1
Physiotherapist		1	1
Psychologist / Neuropsychologist		1	1
Rehabilitation Physician		1	
Speech and Language therapist		1	

Senior HCPs were recruited as they are likely to have an increased understanding of the global TBI care pathway picture and interactions between services brought by experience.

Given the exploratory nature of the research, this list was non-exhaustive. The opportunity was left for the interviewees, who are at the forefront of clinical practice and therefore knowledgeable about the topic investigated, to suggest other suitable interviewees. These further HCPs were recruited using a snowball sampling technique, and interviews were

conducted until saturation of themes was reached [261]. In practice, the additional interviewees were recruited upon recommendation from interviewees, if they found that this new person would have relevant knowledge and experience about the research topic. In this study, this only occurred once, when a trauma coordinator was contacted about interview, and suggested that speaking with a consultant in the rehabilitation unit instead would be more suitable. In terms of data saturation, this was considered reached once the analysis of interview transcripts did not result in new information added to the RADs, in this study, this occurred after 9 interviews, at which point recruitment was interrupted.

Potential participants were identified by key contacts at the study sites and presented with an expression of interest form (Appendix 6.1) and a participant information sheet (Appendix 6.3). For GP recruitment, an ad was placed in the Participate newsletter (Appendix 6.4). Interview dates and time were subsequently decided over email or telephone. The recruitment process is detailed in Figure 6.3.

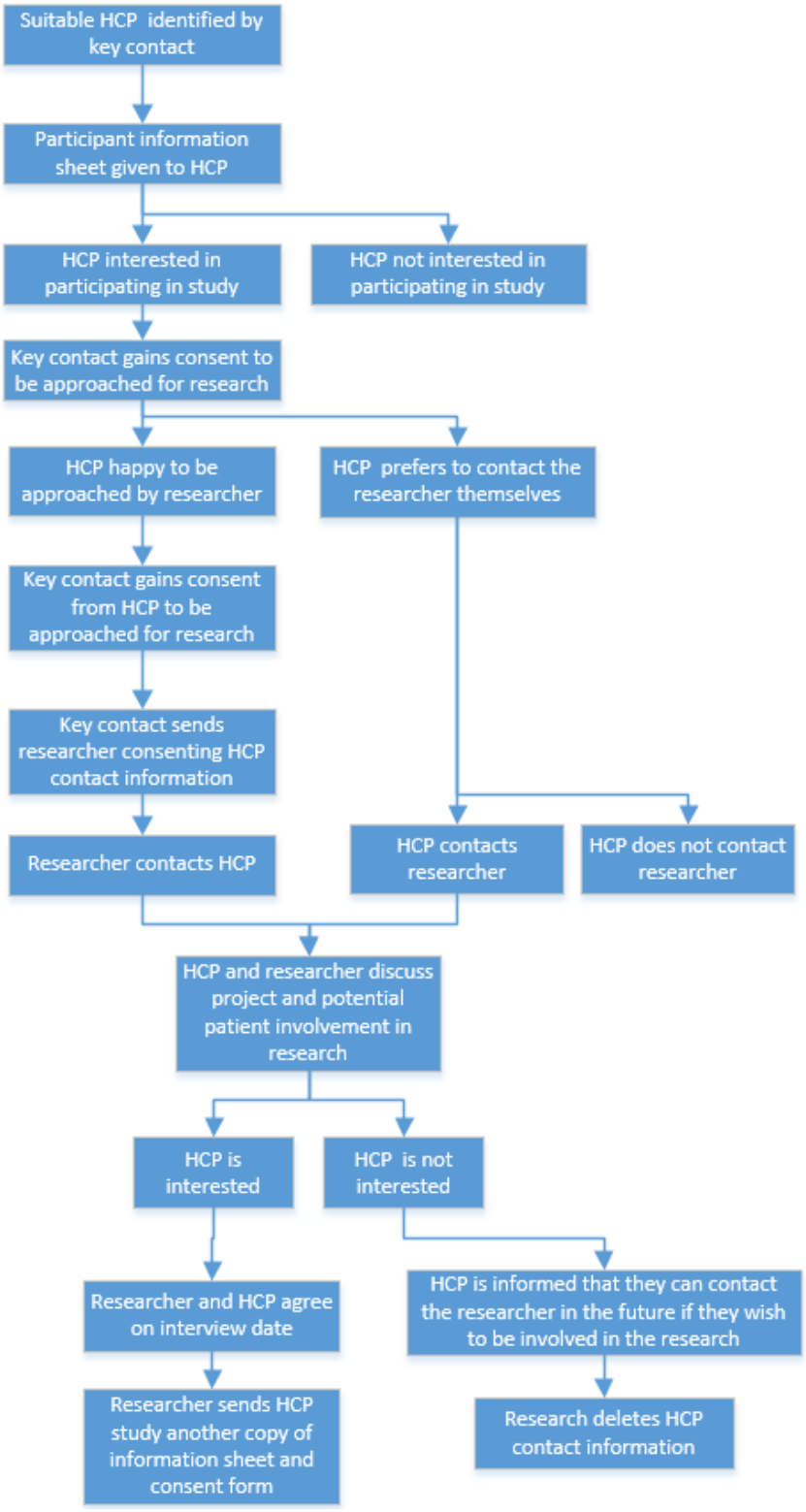


Figure 6.3. Recruitment process for HCP interviews

HCP=Health Care Professional

PROCEDURE AND DATA COLLECTION AND ANALYSIS

Interviews were conducted in staff areas of relevant sites. Each participant had received the participant information sheet when approached by key contacts for participation, and was sent another copy via email when setting up the interview. On the day of the interview, each participant was given a further copy of the participant information sheet and given the opportunity to ask questions. Following this, written consent was obtained using a consent form (Appendix 6.5). Written consent was obtained on the day of the interview, following which the encrypted digital audio recorder was turned on.

The interviews were schedules to last between one to two hours. Themes explored during the interviews are presented in Table 6.4.

Table 6.4. Topic guide for HCP interviews

HCP=Healthcare Professional; TBI=Traumatic Brain Injury

Themes	Aim
Role of HCP within the TBI care pathway	To understand the scope of each HCP role, including tasks and activities
Interaction with other entities	To understand the components of each HCP role in terms of interactions with other HCPs, tools and technologies
Key decisions made by the HCP	To understand the decisions each HCP role makes, including factors informing those decisions, sequences of tasks leading up to decisions, and any protocols or guidelines guiding decisions
Quality Expectations	To understand what quality expectations HCPs have, whether Quality Indicators are used, and how these may affect decision-making.
Data and Information	To understand the types of data and information, formally collected or not, that informs decisions; data systems in place; any gaps in the data that each HCP feels should be collected to meet quality expectations and improve decision-making
Procedure Improvement	To understand the ways in which different HCPs would like to see current care processes improved
Resources	To understand what resources are used by HCPs, to identify any resource gaps and resources needed to meet quality expectations
Handover to other HCPs	To identify referral destinations, challenges in handover, handover processes, and information needed for handovers
Interactions with typical patients	To identify any factors relating to common patient presentations that might impact HCP decision-making
Dealing with atypical scenarios	To understand what uncommon scenarios might affect decision making, and how these would differ from the typical processes

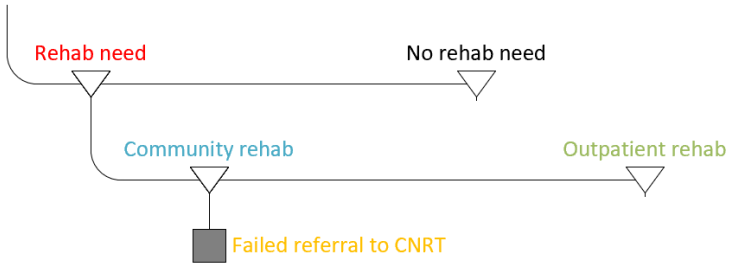
Recordings were transcribed verbatim 48 hours following the interview, to allow time for interviewees to withdraw from the study. Following transcription, the audio recordings

were deleted. Transcribed interviews were password protected and stored on the secure University of Warwick network and hard copies were kept in a locked filing cabinet in a card-access restricted building at Warwick Medical School.

Interview transcripts were analysed using the RAD modelling process.

Example RAD coding

"If there is some motor function difficulties, or functional difficulties, we have a rehab day unit in the Wisdem centre I refer them there. Or the, again this is back to health system and where things go wrong right, there is many patients that you feel will do better with some referral to a specialist community service, and we have a community neurology team, but their condition for admission is to take any patients that is from the hospital. They wouldn't accept a patient that'a already in the community for rehabilitation. "



Following the mapping process, the transcripts were also analysed thematically in NVivo. In NVivo, sections, phrases or words are selected and assigned a code. For example, the transcript section reading "they wouldn't accept a patient that's already in the community" would be coded as "difficulty accessing services" and "restrictive admission criteria". These base level codes are close to the text, and are still numerous. In this study, the initial coding stage yielded 598 initial codes. These are then reviewed, and codes are deduplicated manually, and combined under broader umbrellas. For example, the initial code "importance of face-to-face contact as opposed to generic online information" can be categorised as both "patient education" and "service provision". Codes are grouped together until distinct themes emerge, these final themes are presented in the results section

INTERVIEWEE ROLES

Table 6.5. HCP roles of interviewees

ID	Discipline/specialty	Setting
ID001	Neurorehabilitation consultant	Outpatient
ID002	Clinical psychologist	Acute inpatient and outpatient
ID003	Physiotherapist	Acute inpatient
ID004	Clinical neuropsychologist	Rehabilitation inpatient and outpatient
ID005	Occupational therapist	Rehabilitation inpatient
ID006	Neurorehabilitation consultant	Outpatient
ID007	Occupational therapist	Acute inpatient
ID008	General practitioner	Community
ID009	Charity (Headway) volunteer	Community

The recruitment of these 9 participants fell below the target number set out in the method, however, data saturation was reached with these interviews. More detail about the recruitment difficulties in this study are presented in the discussion.

RAD PATHWAYS

The information collected through interviews was analysed to produce a map of existing pathways for patients with TBI, and specifically focusing on patients with uncomplicated mild TBI. Results from this mapping process are presented through a global overview of the whole pathway first, followed by a detailed description of pathways at each service level. Figures 6.3 to 6.18 are interconnected.

Pathway overview

The pathways spanned 15 services: 6 acute care services, 6 outpatient and community-based healthcare services, 2 charities and 1 unmanaged community setting (patients' home setting) (Figure 6.4).

The data showed a clear break in referral routes between inpatient and outpatient care services. Inpatient services were well interconnected showing clear transfer paths between services. These transitions between services were skewed towards patients with more severe TBIs, or patients with comorbidities. At each service level, routes for the discharge home of patients with milder TBIs not accompanied by obvious deficits were present. Outpatient services were less well interconnected and typically accessible through follow-

up referral for patients who had had an acute care inpatient stay. For patients who had been sent home from A&E, access to further support was largely mediated through GP and charity services.

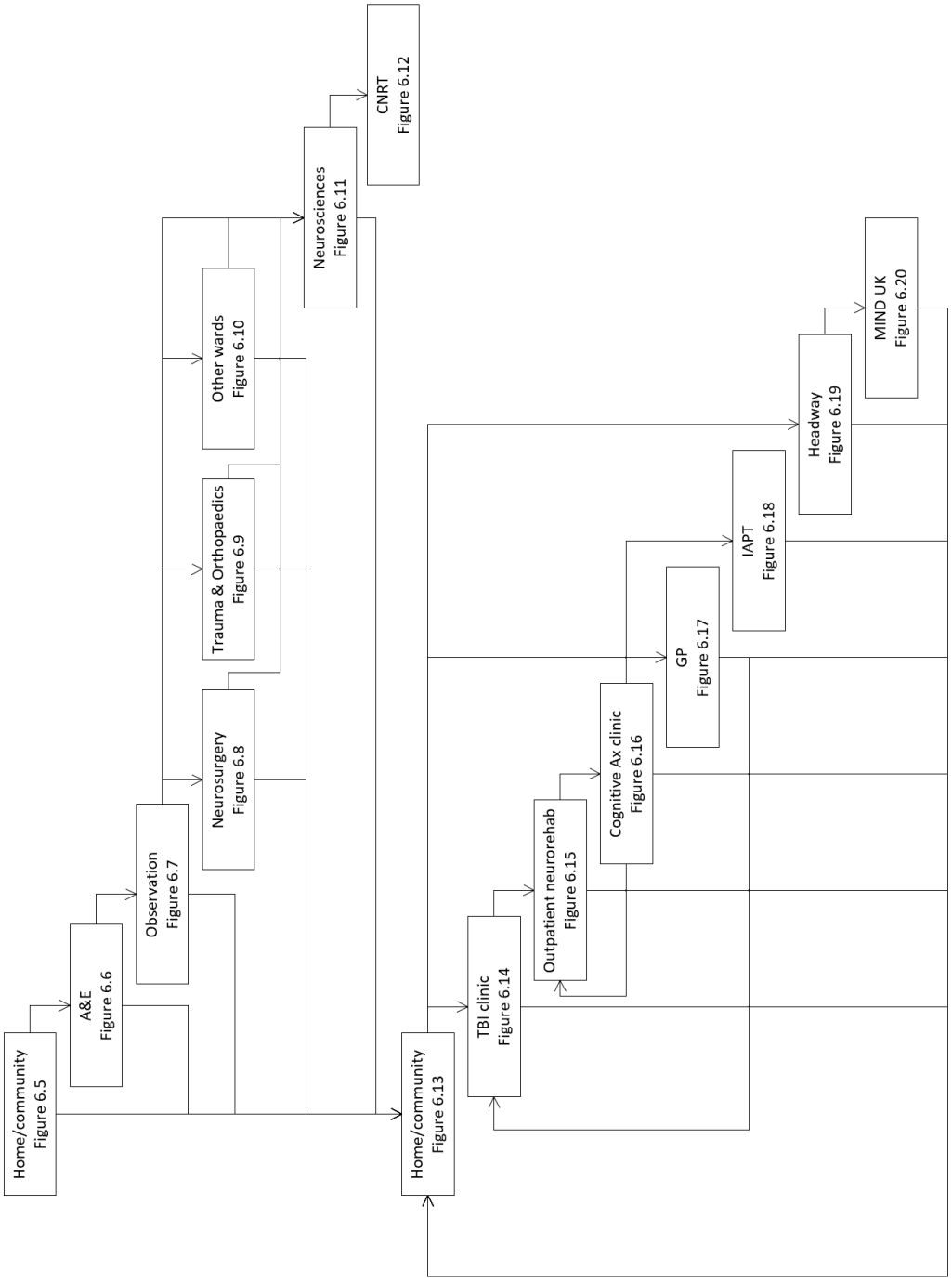


Figure 6.4. Broad pathway map

Home/community (at injury)

Variability in patients access to care starts from the moment of injury, with some patients seeking acute care, while others do not. The data primarily pointed at A&E departments as the main source of acute care services sought out by patients following TBI (Figure 6.5).

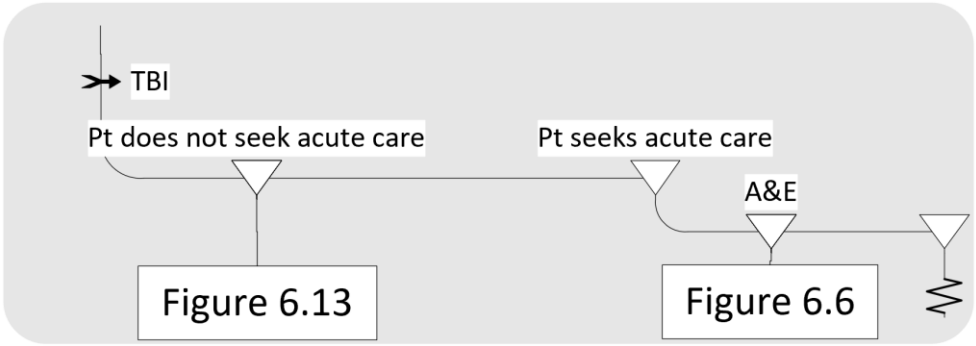


Figure 6.5. Detailed map: home/community (at injury)

Pt=Patient

A&E

At A&E, pathway variability continues based on the nature of the injury. Patients with presenting with an isolated mild TBI without obvious deficits is likely to get discharged home with an information sheet and their GP will be notified. Patients with mild TBI with obvious deficits, more severe TBIs, or TBIs with comorbid injuries will be admitted either for observation or straight to the appropriate ward. An additional group of patients will present at A&E in a polytrauma context in which their TBI may be undetected. These patients will also be admitted into hospital, and their primary presenting injury will determine their destination (Figure 6.6).

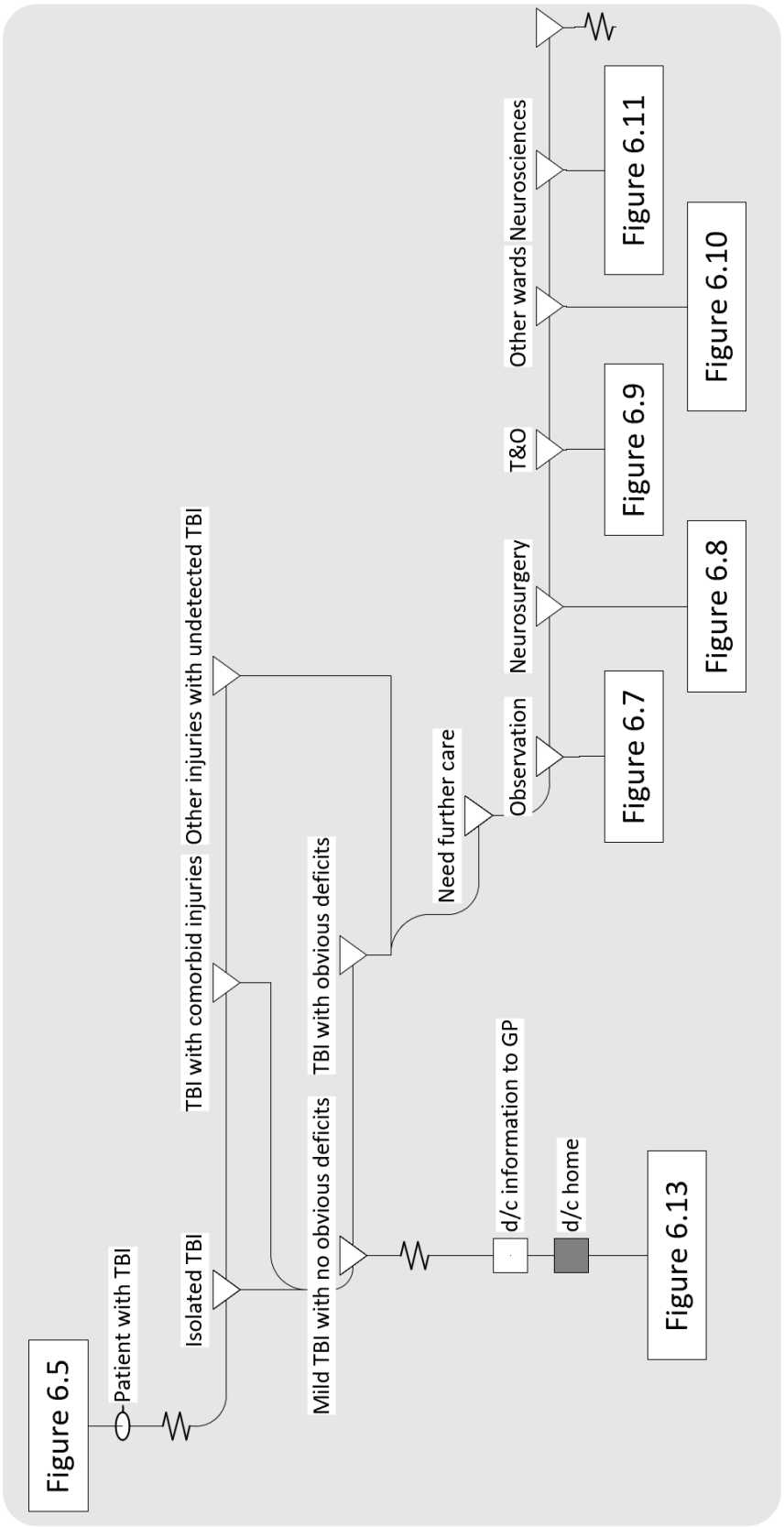


Figure 6.6. Detailed map: A&E

d/c=discharge; T&O=Trauma and Orthopaedics

Observation

Some patients with mild TBI are admitted for observation. At this stage, they may be seen by an alcohol dependency team liaison, their need for pharmacological intervention will be evaluated and addressed. Finally, decisions are made whether to discharge the patient home, repatriate them to their local hospital, or admit them onto one of the wards (Figure 6.7).

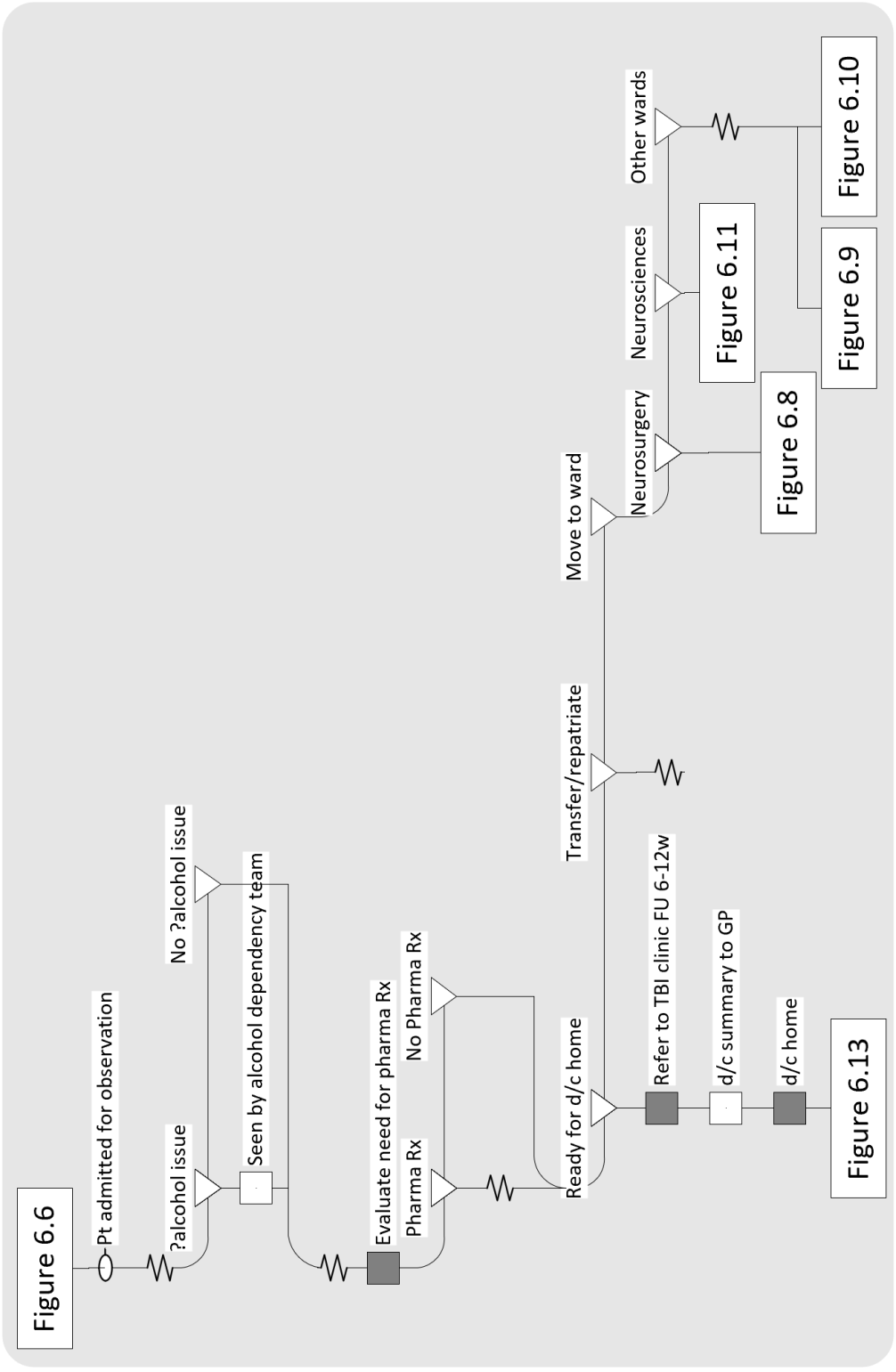


Figure 6.7. Detailed map: observation

Pt=Patient; Rx=Prescription; d/c=discharge

Neurosurgery

The early rehabilitation needs of patients admitted onto the neurosurgery ward are formally assessed by physiotherapists and occupational therapists. At this stage, the team may decide to transfer the patient to the neurosciences ward for further assessment, therapy and onward referrals to inpatient or outpatient rehabilitation services. These patients may have to wait on the neurosurgery ward for an available bed in neurosciences. At this stage, there may be a push to discharge them home in order to free up neurosurgery beds for incoming patients. The brain injury charity Headway has access to patients on these wards to provide them with information about the charity. Patients may decide to reach out to the charity after discharge. (Figure 6.8).

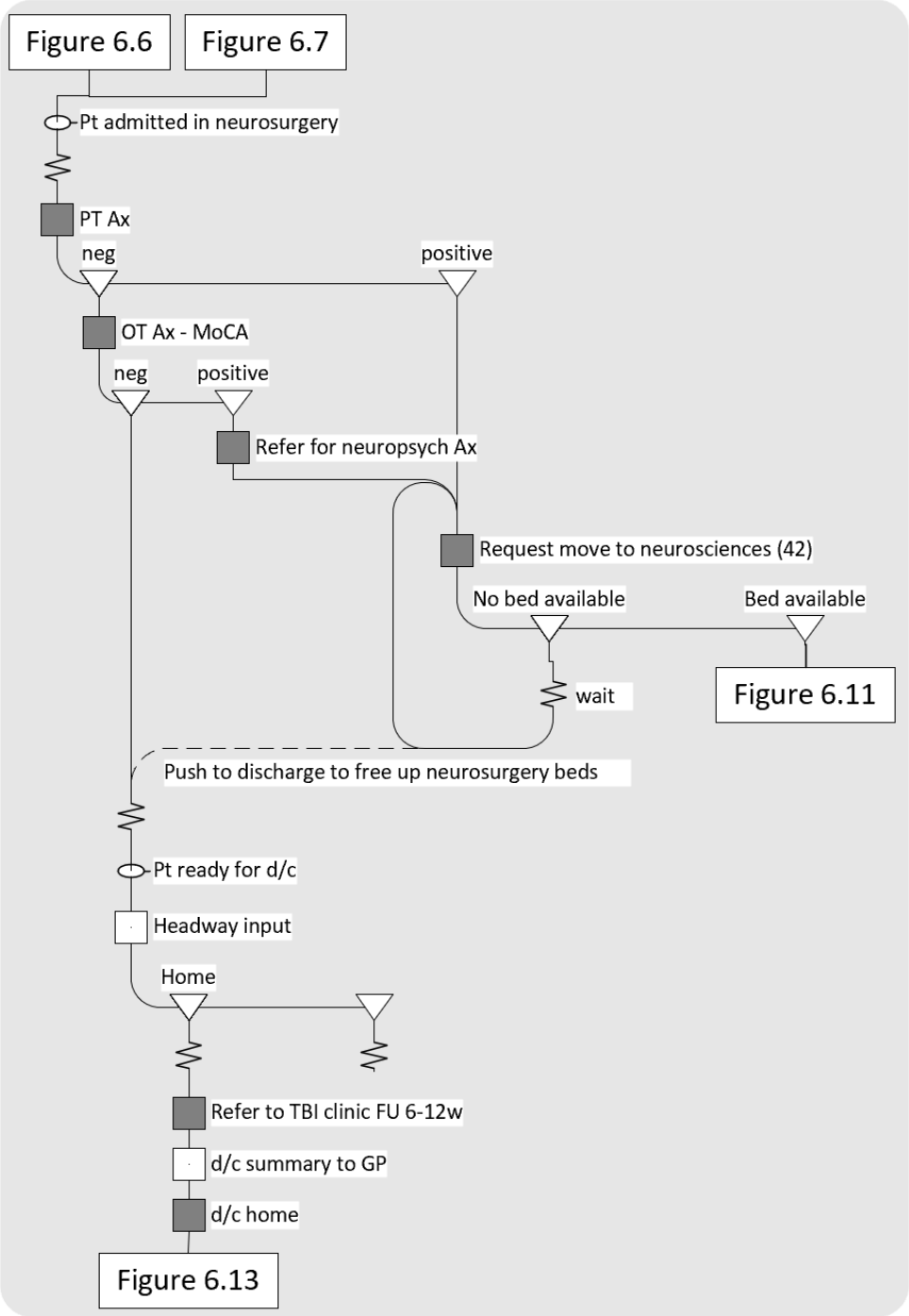


Figure 6.8. Detailed map: neurosurgery

Pt=Patient; PT=Physiotherapy; Ax=Assessment; d/c=discharge; FU=Follow-up

Trauma and Orthopaedics

Patients treated on the trauma and orthopaedics ward are on a major trauma pathway, which includes formal cognitive screening. At this stage, they may be identified as having potential longer-term rehabilitation needs and are therefore transferred to the

neurosciences ward for further assessment, therapy, and onward referral. Similar to the situation on the neurosurgery ward, it may be that some patients waiting for a free bed on the neurosciences ward are discharged home to free up trauma and orthopaedics beds for incoming patients. Headway volunteers do not have access to patients on this ward (Figure 6.9).

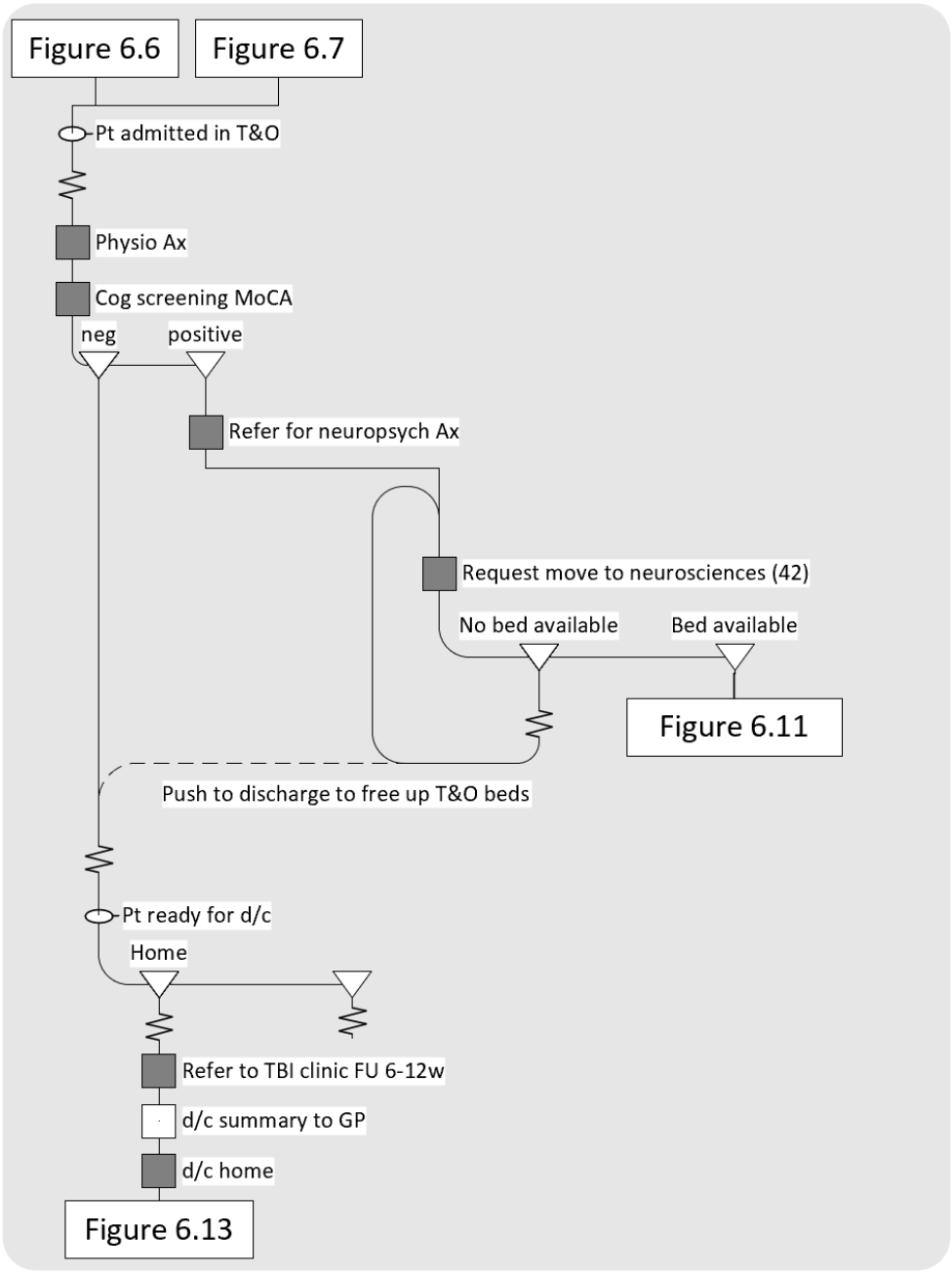


Figure 6.9. Detailed map: trauma and orthopaedics

Pt=Patient; T&O=Trauma and Orthopaedics; Ax=Assessment; Cog=cognitive; MoCA=Montreal Cognitive Assessment; neg=negative; d/c=discharge; TBI=Traumatic Brain Injury; FU=Follow-up

Other acute wards

Patients with TBIs and other brain injuries may also be treated on other wards in the first instance, depending on the extent of comorbid injuries at presentation. There is no set process for cognitive screening of patients on wards other than neurosurgery and trauma and orthopaedics. Therefore, identification of patients who may need neurorehabilitation input may only occur if the therapy staff working on the ward are attuned to cognitive impairment. When such patients are identified, therapy staff may contact their specialist colleagues from the neurosurgery or neurosciences wards for screening. In turn, they may refer identified patients to the neurosciences ward. As with the other acute wards described previously, there may be a push to discharge patients waiting for a bed in neurosciences (Figure 6.10).

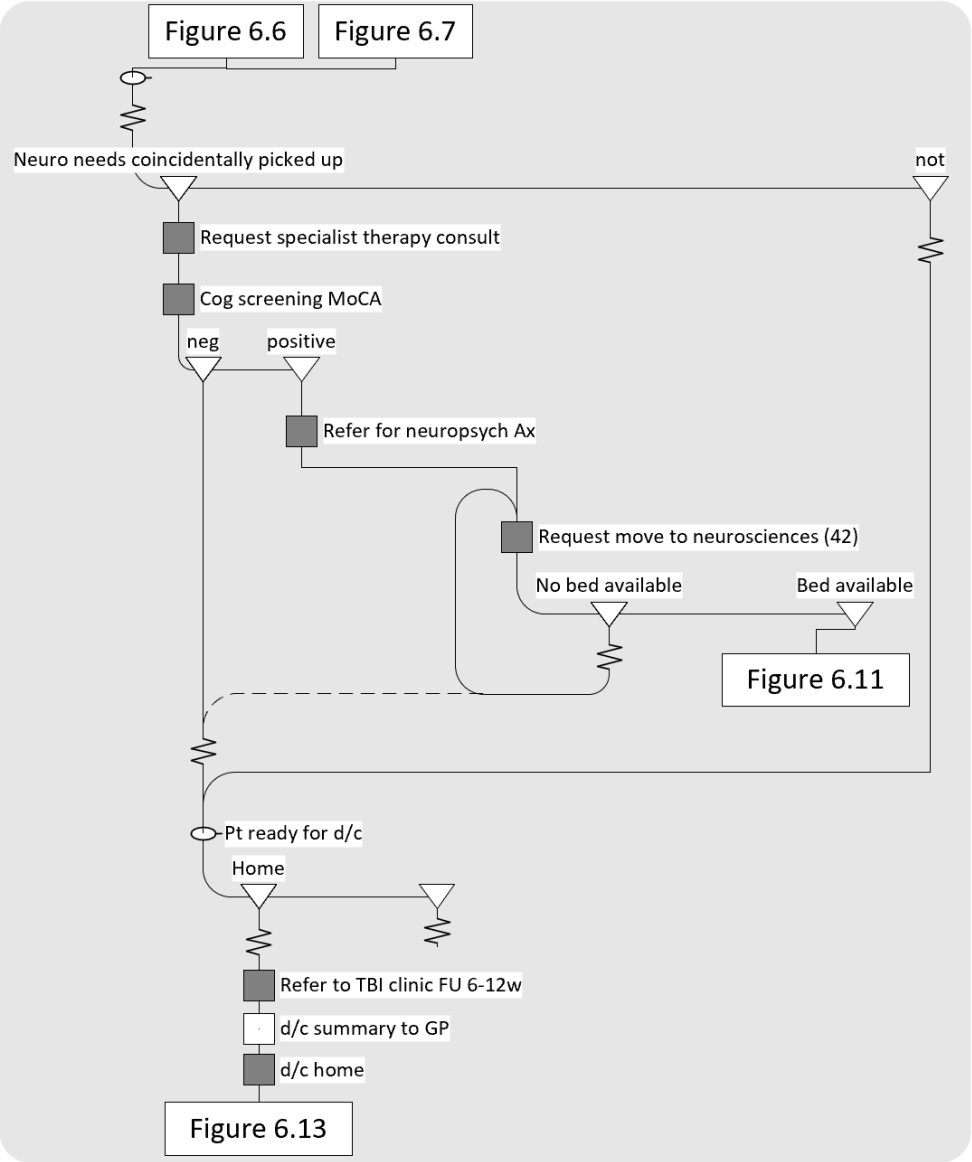


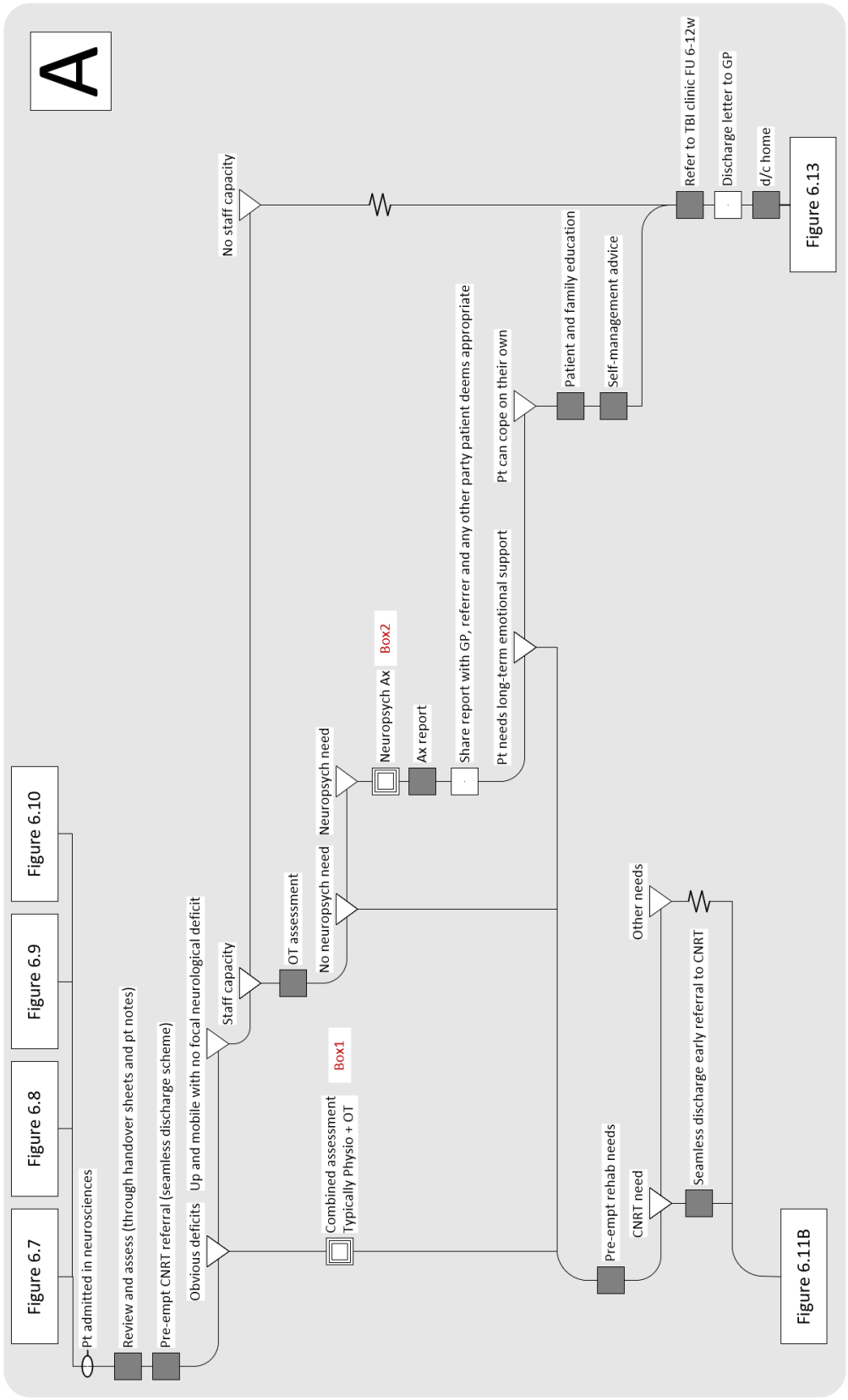
Figure 6.10. Detailed map: other wards

Pt=Patient; Ax=Assessment; Cog=cognitive; MoCA=Montreal Cognitive Assessment; d/c=discharge; FU=Follow-up

Neurosciences

The notes of patients admitted onto the neurosciences wards are reviewed in order to pre-empt any necessary referral to the Community Neurorehabilitation Team (CNRT). This process is part of a seamless discharge scheme designed to minimise delay and gaps in care between inpatient and community-based care. Following this initial review, a multidisciplinary assessment of each patient is conducted. This assessment typically combines occupational therapy and physiotherapy (Box 1, Appendix 6.6), although other specialties may be involved, such as speech and language therapy, depending on the patient profile. Because of limited staffing, patients with obvious deficits are prioritised for these assessments. Patients who are up and mobile with no obvious neurological deficits are

assessed, if there is staff capacity, by an occupational therapist, who may then identify needs for a detailed neuropsychological assessment (Box 2, Appendix 6.7). Patients who are deemed capable of coping on their own without further therapies input, or those without obvious deficits who did not benefit from a detailed assessment are discharged home with a referral to the brain injury clinic. Patients who are deemed to have support needs are divided into those with low rehabilitation potential, who are discharged to a discharge to assess bed, or receive a direct placement to a care home. Destinations for onward referral of patients with higher rehabilitation potential are largely based on their postcode. For example, patients from Northamptonshire (which falls within the remit of the West Midlands Major Trauma Network) with low needs may be referred to their local brain injury team, and those with higher needs will be repatriated to their local hospital. Patients from Coventry and Warwickshire can be referred to inpatient level 1 or 2b neurorehabilitation, outpatient neurorehabilitation services, or the CNRT (facilitating this referral through the seamless discharge scheme). It may be that there is no appropriate discharge destination for some patients, notably for those who do not have multidisciplinary input needs. For these, a more in-depth functional assessment is conducted to evaluate whether they may be fit for discharge home or whether rehabilitation referral options need to be re-evaluated. Patients on the neurosciences ward benefit from Headway input prior to discharge and are referred for follow-up in the brain injury clinic (Figure 6.11).


A
Figure 6.7
Figure 6.8
Figure 6.9
Figure 6.10
Pt admitted in neurosciences
Review and assess (through handover sheets and pt notes)
Pre-empt CNRT referral (seamless discharge scheme)
Obvious deficits
Up and mobile with no focal neurological deficit
Staff capacity
No staff capacity
OT assessment
Combined assessment
Typically Physio + OT
Box1
No neuropsych need
Neuropsych need
Neuropsych Ax
Box2
Ax report
Share report with GP, referrer and any other party patient deems appropriate
Pt needs long-term emotional support
Pt can cope on their own
Patient and family education
Self-management advice
Refer to TBI clinic FU 6-12w
Discharge letter to GP
d/c home
Figure 6.13
Pre-empt rehab needs
CNRT need
Other needs
Seamless discharge early referral to CNRT
Figure 6.11B

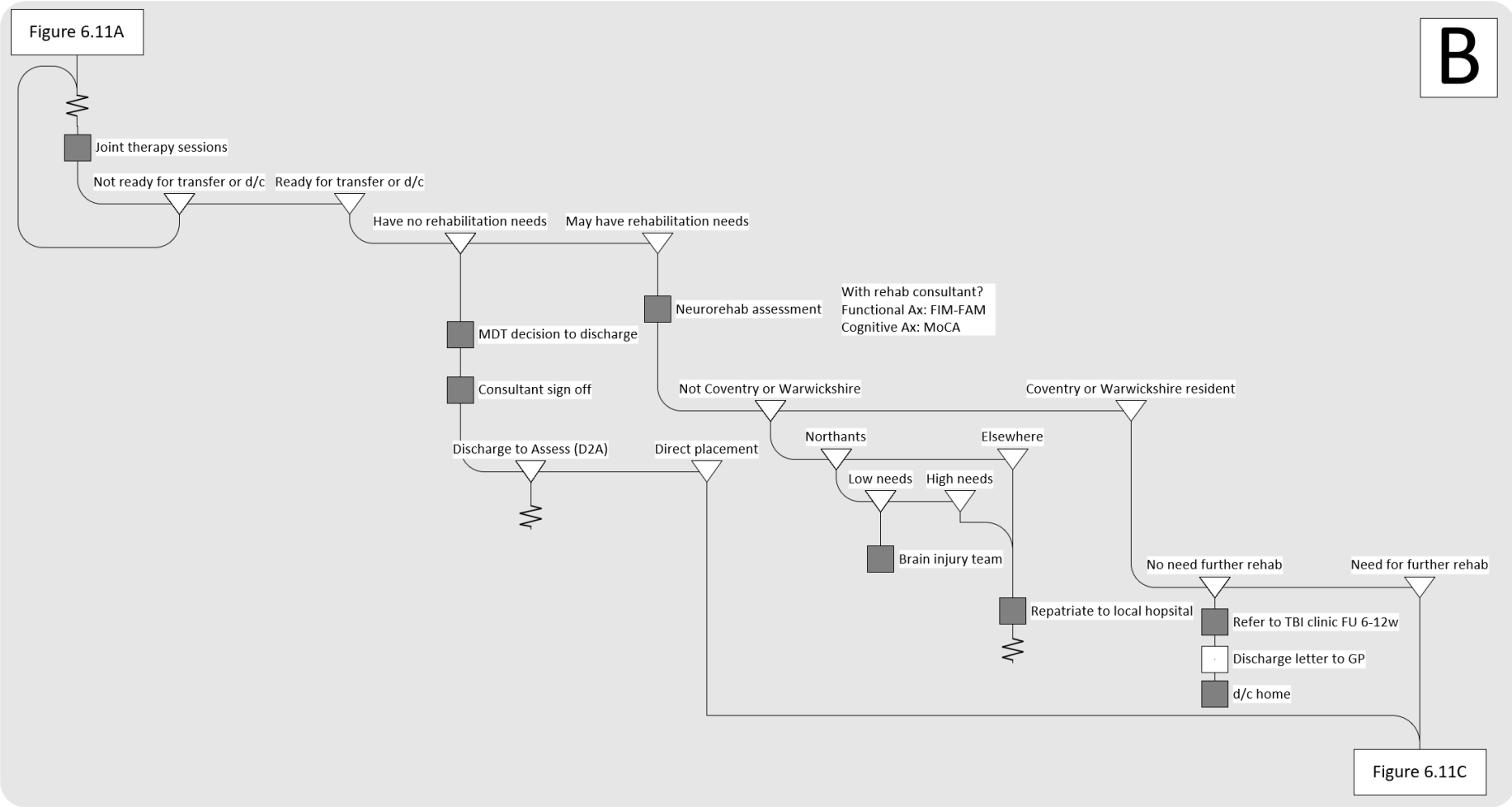


Figure 6.11A
B
Joint therapy sessions
Not ready for transfer or d/c
Ready for transfer or d/c
Have no rehabilitation needs
May have rehabilitation needs
Neurorehab assessment
With rehab consultant?
Functional Ax: FIM-FAM
Cognitive Ax: MoCA
MDT decision to discharge
Consultant sign off
Not Coventry or Warwickshire
Coventry or Warwickshire resident
Northants
Elsewhere
Discharge to Assess (D2A)
Direct placement
Low needs
High needs
Brain injury team
No need further rehab
Need for further rehab
Repatriate to local hopsital
Refer to TBI clinic FU 6-12w
Discharge letter to GP
d/c home
Figure 6.11C

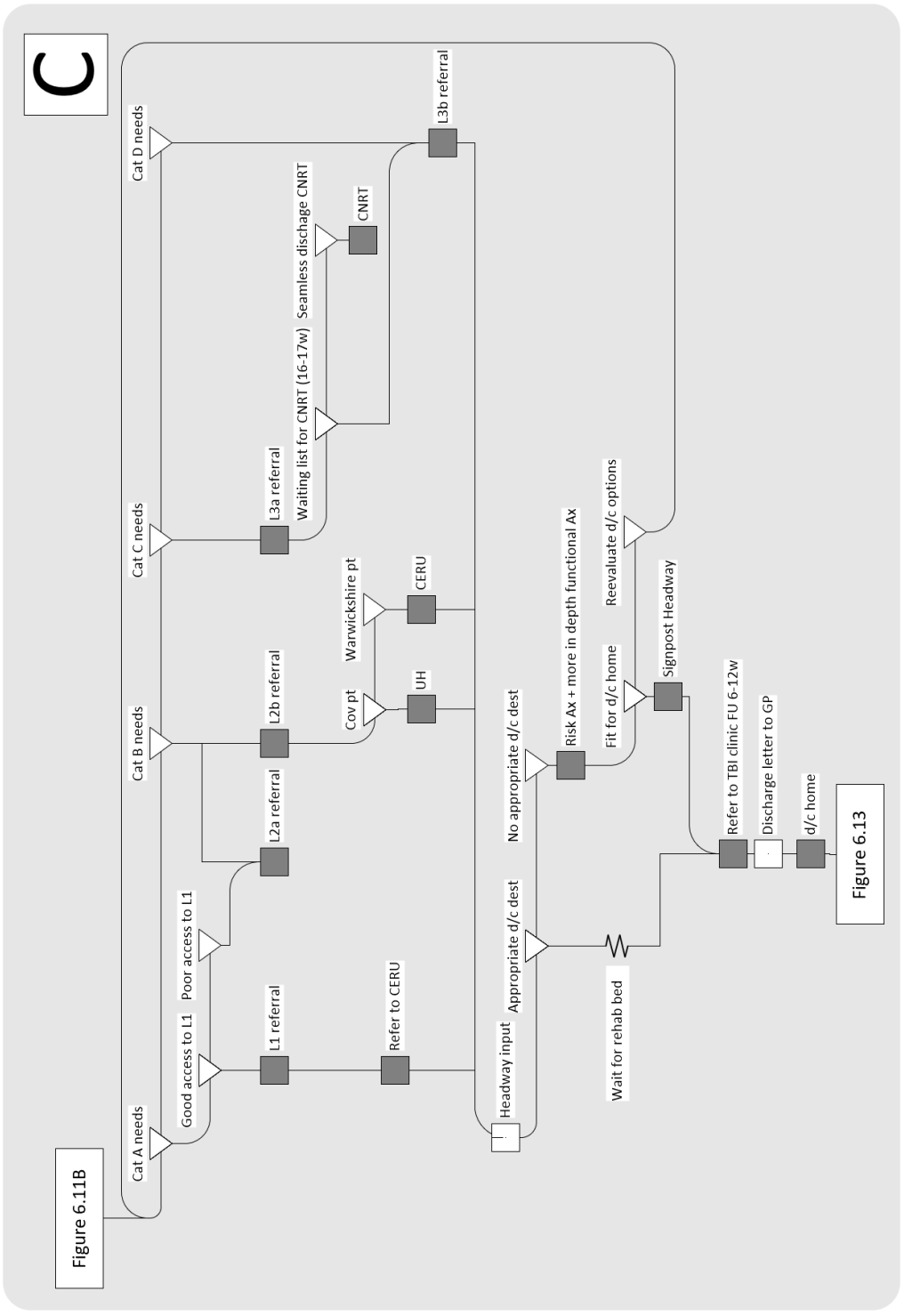


Figure 6.11. Detailed map: neurosciences

Pt=patient; CNRT=Community NeuroRehabilitation Team; OT=Occupational Therapy; Ax=Assessment; FU=Follow-up; d/c=discharge; MDT=MultiDisciplinary Team; MoCA=Montreal Cognitive Assessment; FIM-FAM=Functional Independence Measure and Functional Assessment Measure; CERU=Central England Rehabilitation Unit; L1/2a/2b/3a=Rehabilitation service level

Community Neurorehabilitation Team

Patients discharged from the neurosciences ward may be referred to the CNRT. Members of the CNRT could not be interviewed for this project, however, concordant views emerging from the data suggest that they are unlikely to accept referrals for patients with milder TBIs who are not deemed to need multidisciplinary specialist input (Figure 6.12).

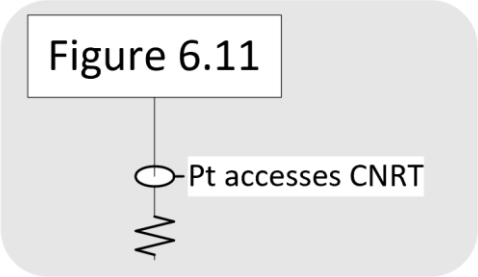


Figure 6.12. Detailed map: CNRT

Pt=patient; CNRT=Community Neurorehabilitation Team

Home community (post-injury)

Patients who are home in the community following TBI may experience no further problems, no complications prompting a visit to A&E, and no persisting symptoms. Patients at home following TBI who have been admitted into hospital at least for observation have a follow up appointment at the brain injury clinic, which they may decide to attend or not. People who experience persisting symptoms may decide to seek support through their GP or charity organisations, while some may not. Those who have persisting symptoms but do not access support are at risk of falling into a 'spiral of descent' in which things get progressively worse in terms of their symptoms, but also their ability to be a fully participating member of their community (i.e. relationship breakdown, loss of employment, financial difficulties).

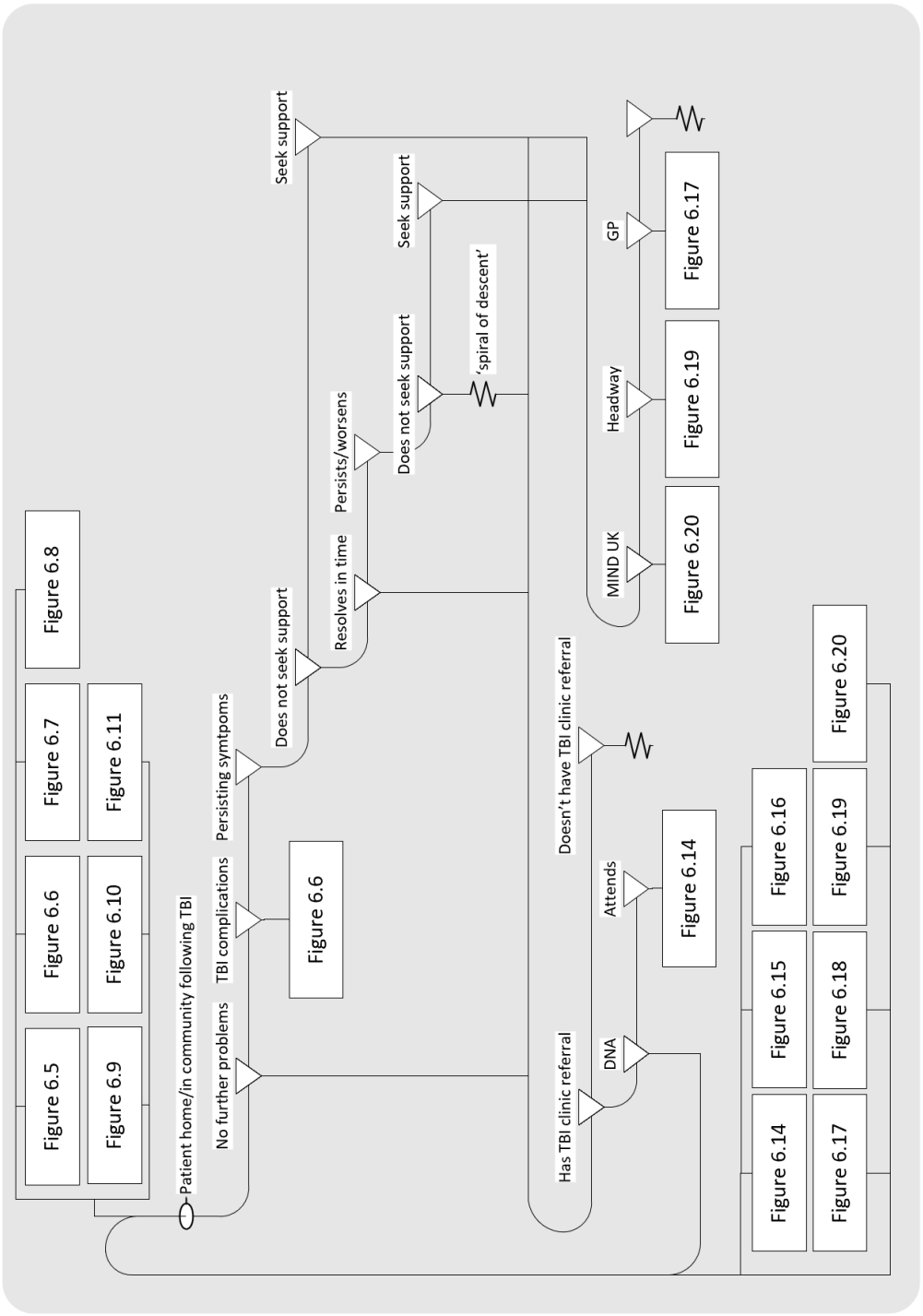


Figure 6.13. Detailed map: home/community (post-injury)

DNA=Did Not Attend

Brain injury clinic

The consultant-led brain injury clinic offers appointments to any patient who has been admitted to hospital following A&E attendance with TBI. In these clinics, a detailed assessment of the patient and an evaluation any rehabilitation needs are conducted. Based on this information, consultants can make referrals to the appropriate rehabilitation service, including both inpatient and outpatient. Patients with P-TBI-S are most likely to need outpatient specialist or community rehabilitation. The limits of community-based rehabilitation services in the area were highlighted: in Coventry, the only appropriate service is the CNRT, and there is no equivalent in South Warwickshire. The CNRT however only accepts referrals coming from inpatient settings. As such, patients with milder injuries and who were consequently not admitted in the neurosciences ward are very unlikely to be able to access CNRT for rehabilitation. At this stage, the neurorehabilitation consultant can attempt to refer this patient to specialist outpatient rehabilitation services, many of which have an admission requirement that the patient has multidisciplinary needs, which may not be the case for a number of patients with P-TBI-S. The remaining option for the neurorehabilitation consultant is to refer to non-specialist services, or argue for their patient's need of multidisciplinary involvement and push for admission into specialist services.

Any patient admitted into hospital for observation or directly to wards following TBI is given a referral for follow-up in an outpatient brain injury clinic 6 to 12 weeks from discharge. Attendance to the brain injury clinic for such follow-ups was deemed poor by the consultants. Attendance to brain injury clinic for follow-up included evaluation of rehabilitation needs and prompted referral to rehabilitation services based on the level and complexity of needs. Patient with milder TBIs with primarily subtle cognitive or emotional support needs that are not deemed manageable through patient education and unsupported self-management alone are typically referred to a cognitive assessment clinic and/or outpatient neurorehabilitation services as needed. Patients going down that route are also periodically re-evaluated in the brain injury clinic.

Neurorehabilitation consultants in the brain injury clinic and therapists in the outpatient neurorehabilitation service pointed out that people with very subtle impairments typically fall through the gaps of healthcare at this point because they do not meet the needs threshold for admission to further care services, and therefore would have not been referred to the brain injury clinic in the first place (Figure 6.14).

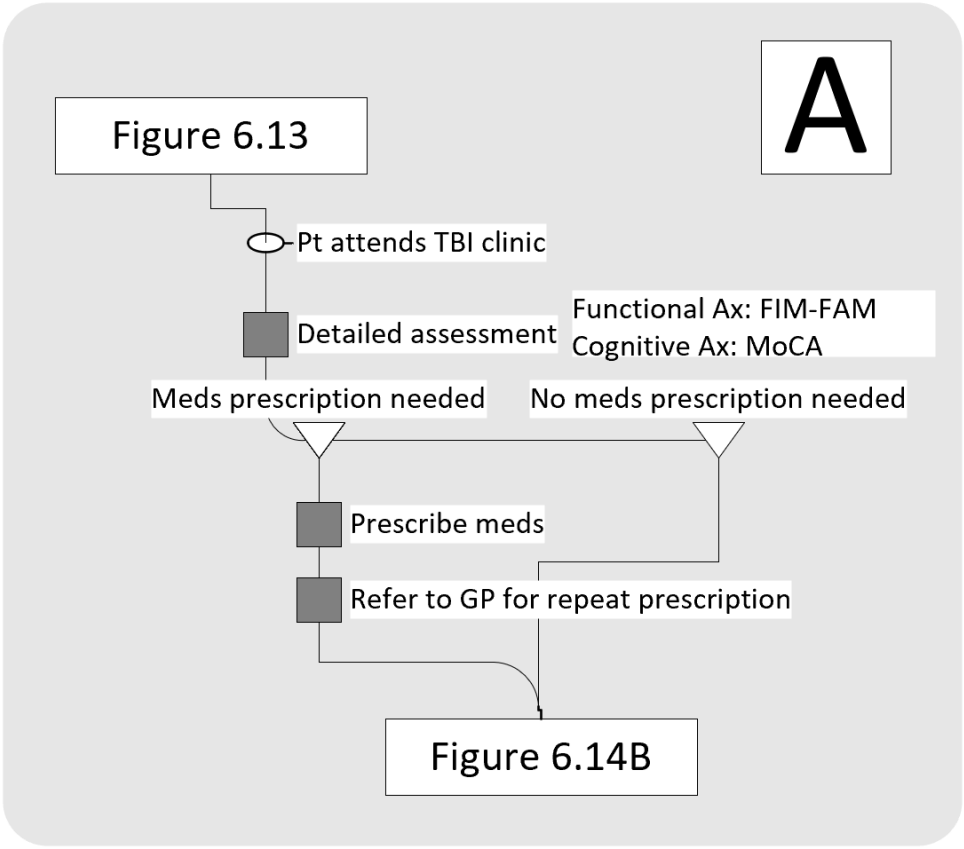
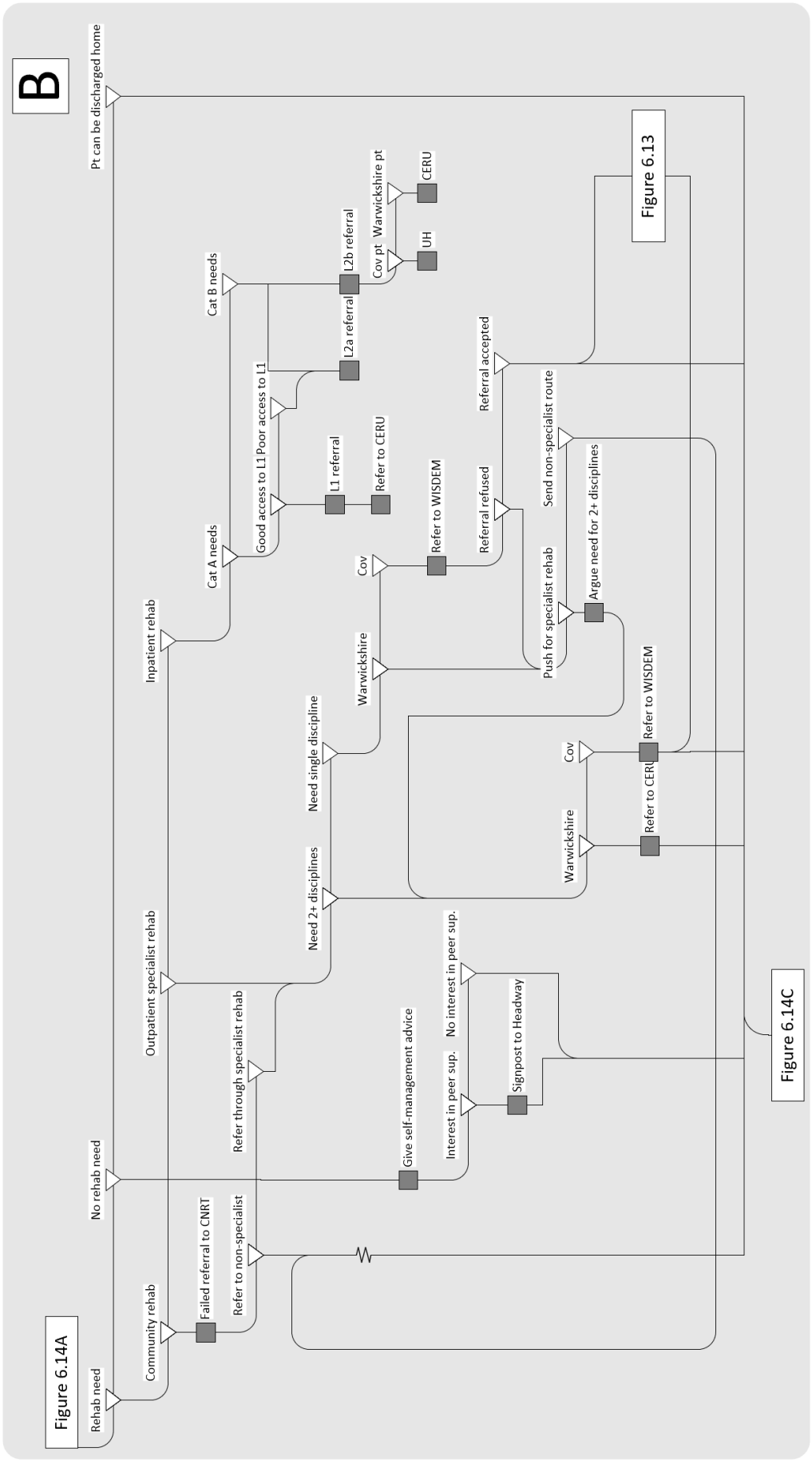


Figure 6.13
A
Pt attends TBI clinic
Detailed assessment
Functional Ax: FIM-FAM
Cognitive Ax: MoCA
Meds prescription needed
No meds prescription needed
Prescribe meds
Refer to GP for repeat prescription
Figure 6.14B


B
Pt can be discharged home
Figure 6.13
Cat B needs
L2b referral
Cov pt
Warwickshire pt
CERU
UH
L2a referral
Referral accepted
Good access to L1
Poor access to L1
L1 referral
Refer to CERU
Cat A needs
Cov
Refer to WISDEM
Referral refused
Send non-specialist route
Inpatient rehab
Warwickshire
Push for specialist rehab
Argue need for 2+ disciplines
Need single discipline
Cov
Refer to WISDEM
Refer to CERU
Warwickshire
Need 2+ disciplines
Outpatient specialist rehab
No interest in peer sup.
Refer through specialist rehab
Give self-management advice
Interest in peer sup.
Signpost to Headway
No rehab need
Failed referral to CNRT
Refer to non-specialist
Community rehab
Rehab need
Figure 6.14A
Figure 6.14C

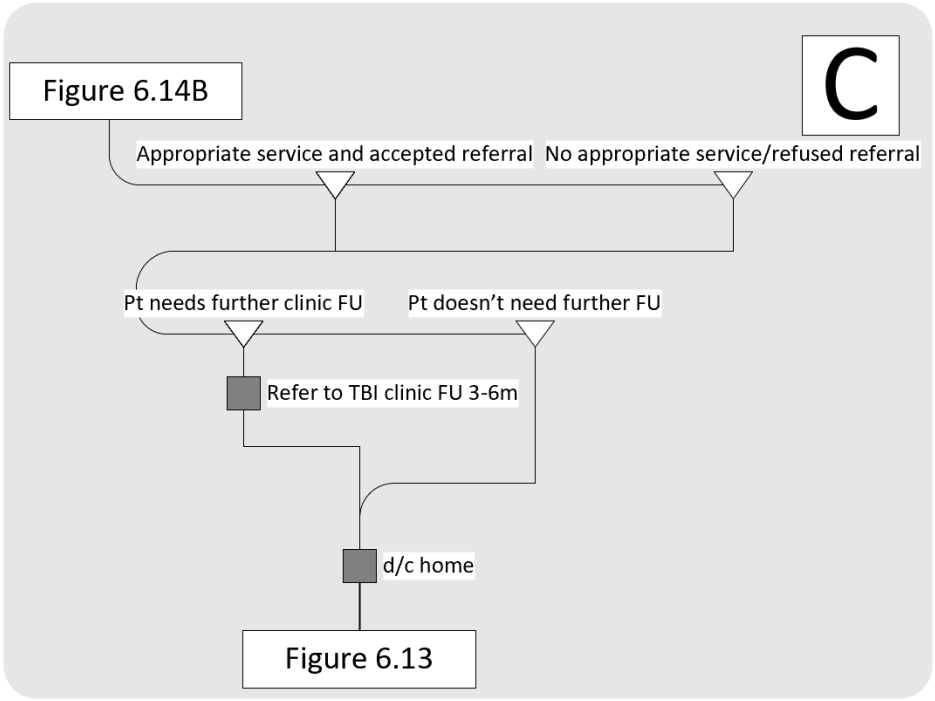


Figure 6.14. Detailed map: brain injury clinic

FIM-FAM=Functional Independence Measure and Functional Assessment Measure; MoCA=Montreal Cognitive Assessment; L1/2a/2b/3a=Rehabilitation service level; Cov=Coventry; CERU= Central England Rehabilitation Unit; WISDEM=centre at University Hospital Coventry and Warwickshire providing outpatient rehabilitation services; UH=University Hospital Coventry and Warwickshire; Pt=patient; FU=Follow-up; d/c=discharge

Outpatient neurorehabilitation

Patients presenting for outpatient neurorehabilitation may have been referred to one or more specialties, including psychology, occupational therapy and physiotherapy. These specialists do not operate as part of a multidisciplinary team and separate rehabilitation goals are set with patients in each specialty. As such a patient may be discharged from one discipline while still working with another. There are referral options between the therapists. For example, should a patient receiving occupational therapy show signs of cognitive or emotional difficulties, their occupational therapist may refer them to a psychology colleague. Psychologists may refer patients to the cognitive assessment clinic to obtain a detailed profile of the patient and their needs. Upon achievement of rehabilitation goals, patients are discharged home (Figure 6.15).

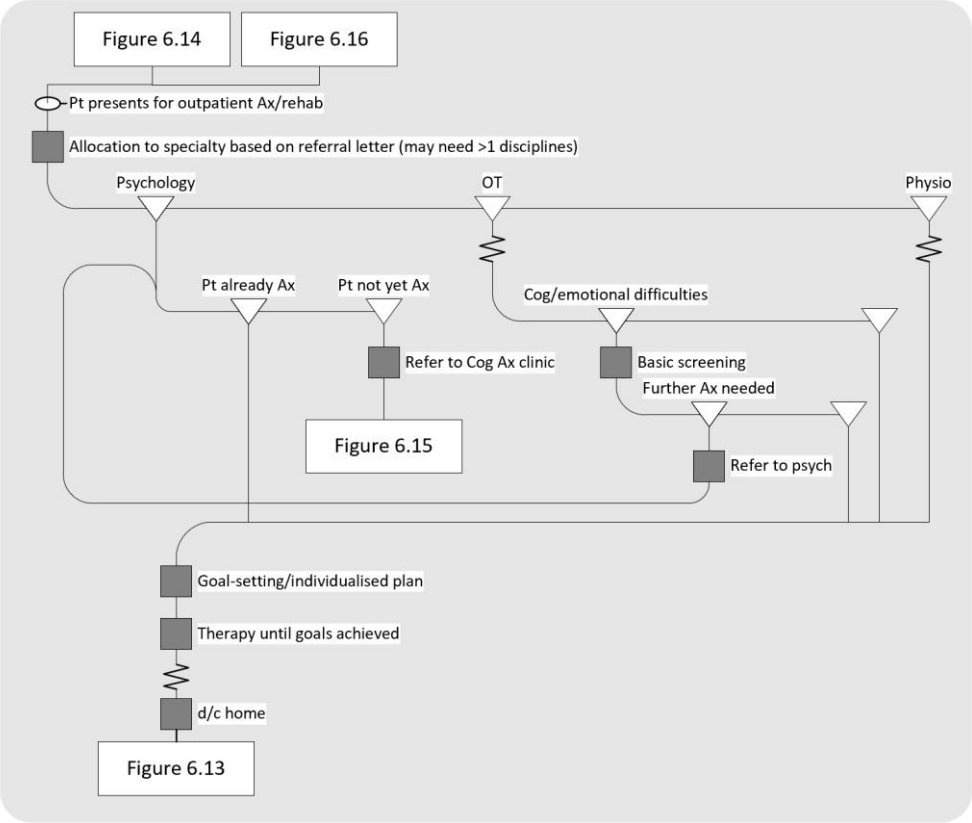


Figure 6.15. Detailed map: outpatient neurorehabilitation

Pt=patient; Ax=Assessment; d/c=discharge

Cognitive assessment clinic

Patients attending the cognitive assessment clinic undergo a detailed neuropsychological assessment that comprises multiple standard measures and is tailored to their presenting characteristics (i.e. evidence of suicidal ideation, premorbid IQ) (Box 2, Appendix 6.7). Patients needing long-term support can be referred to outpatient neurorehabilitation services when they are available locally. Coventry patients may be referred to the WISDEM centre, South Warwickshire patients to the day-unit at the Central England Rehabilitation Unit. Patients from Northamptonshire may be referred to the community brain injury team. Patients from areas without community rehabilitation services will be directed towards Improving Access to Psychological Therapies (IAPT) services. Following assessment, some patients may be deemed to be able to cope on their own without further rehabilitation input. These patients will receive education about brain injury and its consequences, provided with some self-management advice, and be discharged home.

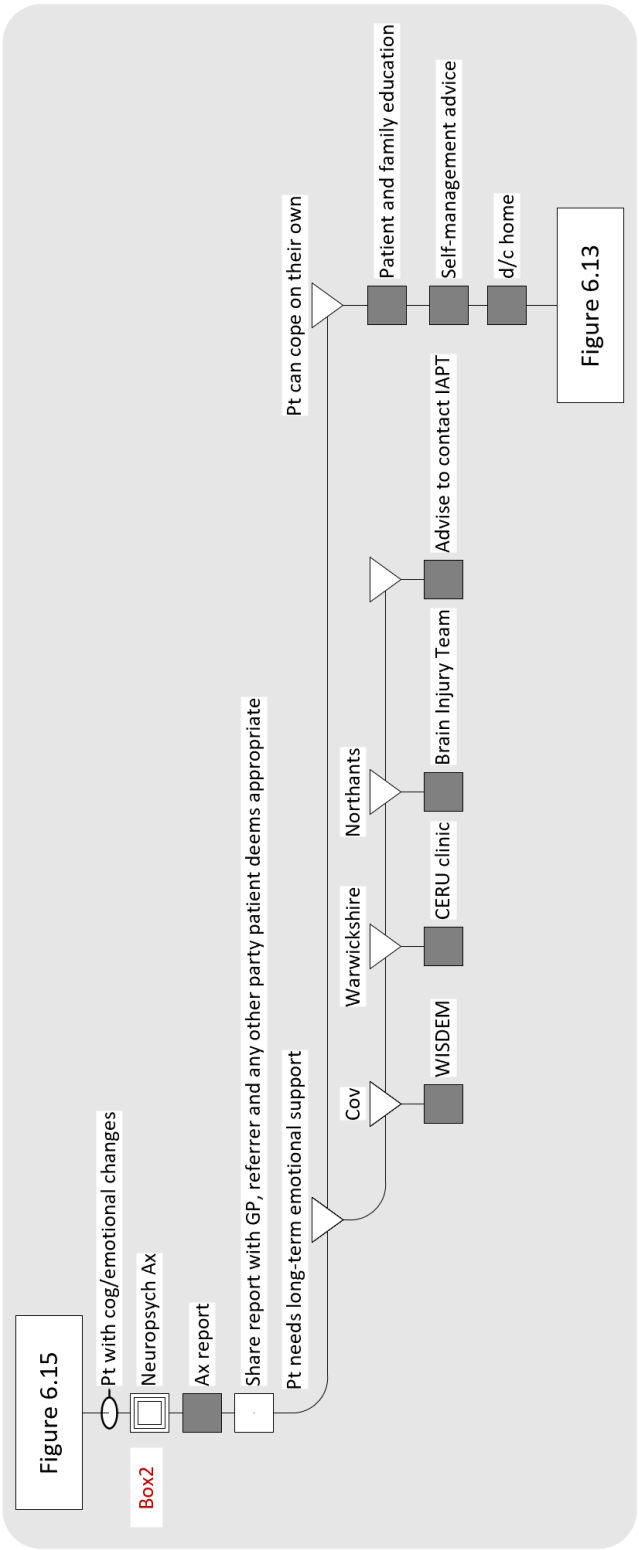


Figure 6.16. Detailed map: cognitive assessment clinic

Pt=patient; Ax=Assessment; Cov=Coventry; Northants=Northamptonshire; WISDEM=centre at University Hospital Coventry and Warwickshire providing outpatient rehabilitation services; CERU=Central England Rehabilitation Unit; IAPT=Improving Access to Psychological Therapies; d/c=discharge

General Practice

For patients who were discharged from A&E without admission, and indeed those who did not seek acute care, the sole route for access to healthcare support is through general practice. The GP then has to evaluate whether the patient can be managed in primary care, using reassurance, education and self-management. When the patient's condition is not deemed manageable in primary care, the GP has limited referral options: the brain injury clinic, a neurologist if neurological signs are present, or other specialist clinics and clinicians where there is diagnostic uncertainty. GPs also have the option to signpost to charity services, of which Headway is commonly used for patients with brain injury. They can also offer pharmacological symptoms management.

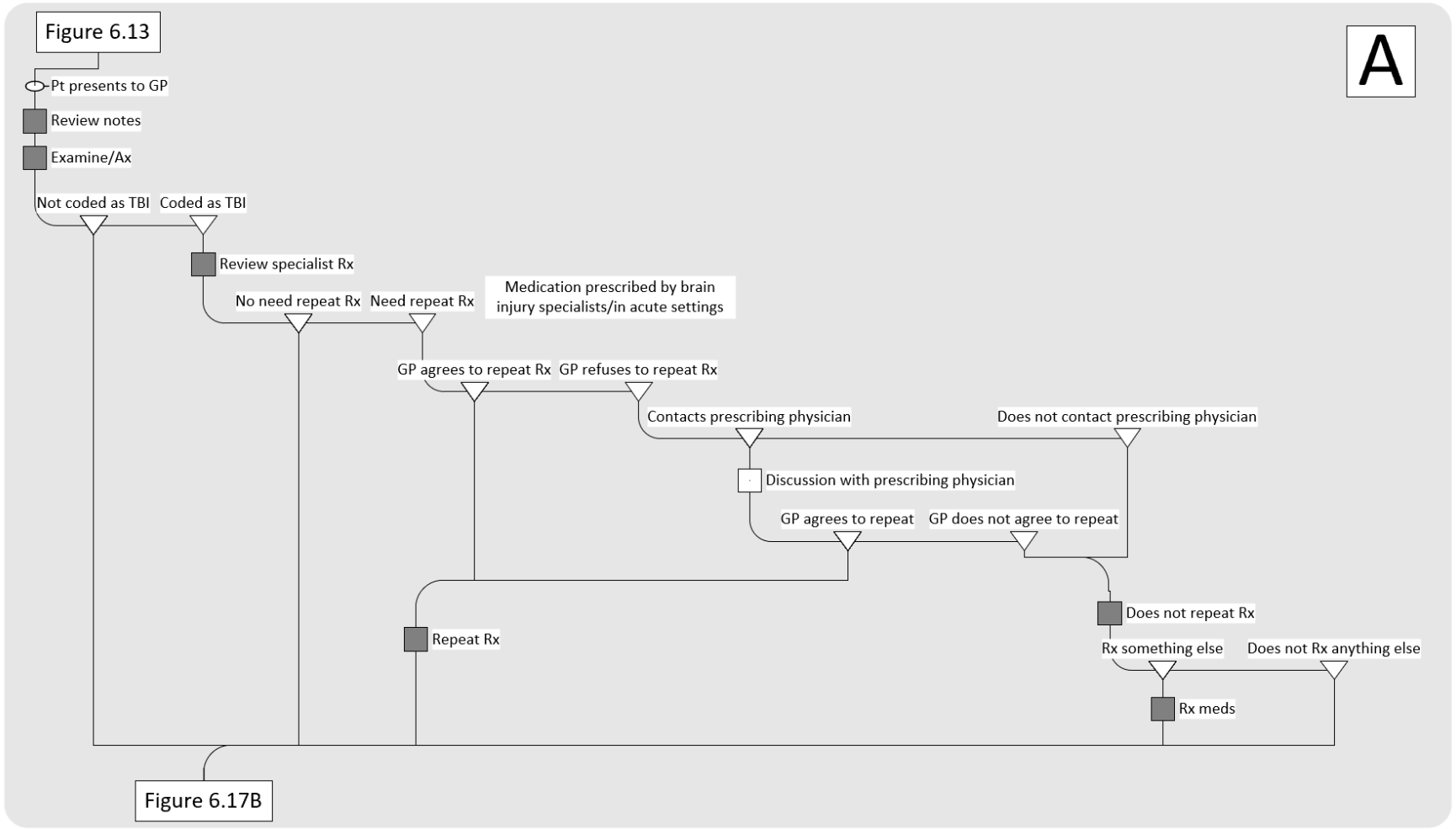


Figure 6.13
A
Pt presents to GP
Review notes
Examine/Ax
Not coded as TBI
Coded as TBI
Review specialist Rx
No need repeat Rx
Need repeat Rx
Medication prescribed by brain injury specialists/in acute settings
GP agrees to repeat Rx
GP refuses to repeat Rx
Contacts prescribing physician
Does not contact prescribing physician
Discussion with prescribing physician
GP agrees to repeat
GP does not agree to repeat
Repeat Rx
Does not repeat Rx
Rx something else
Does not Rx anything else
Rx meds
Figure 6.17B

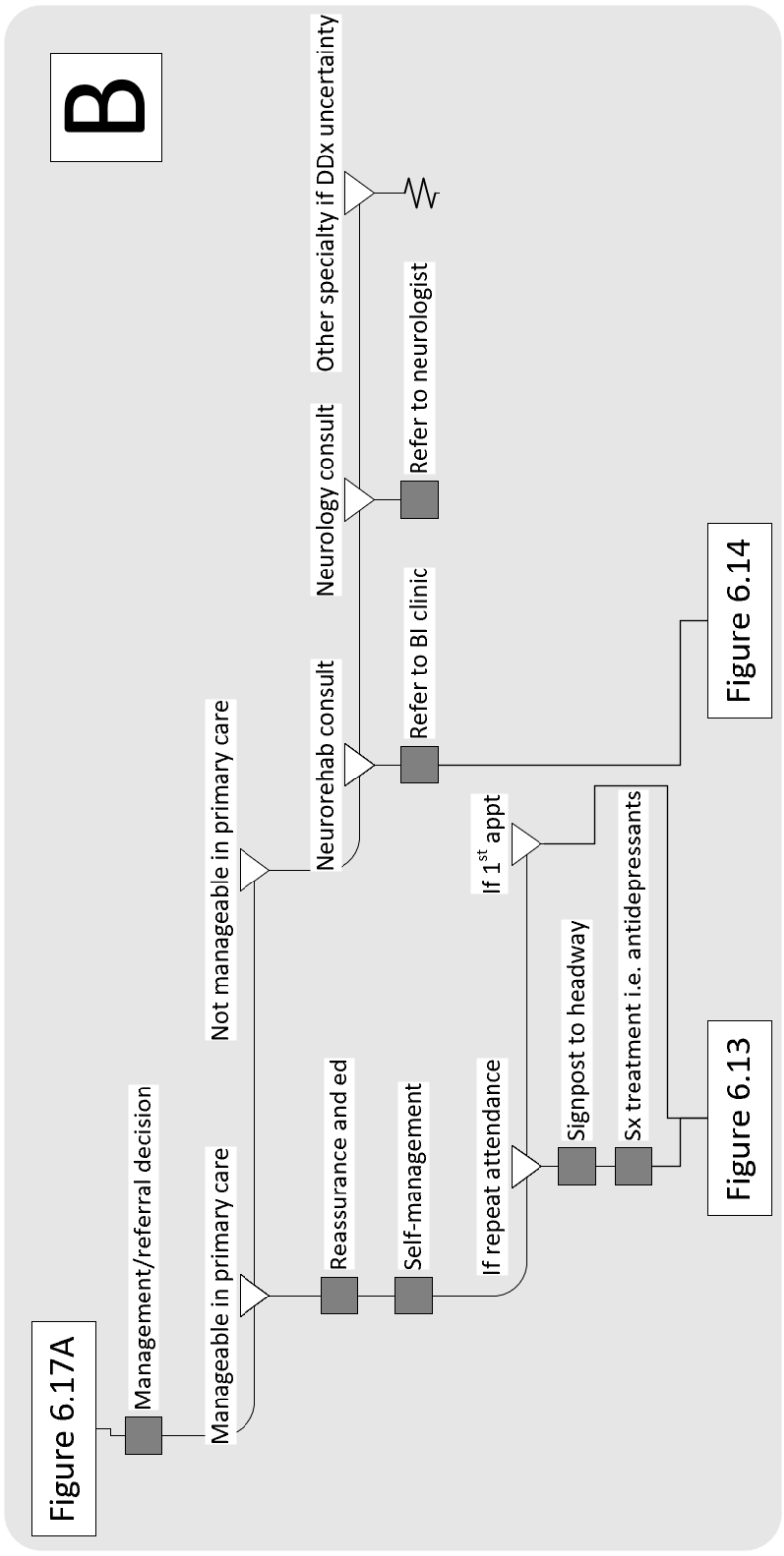


Figure 6.17. Detailed map: GP

Pt=patient; Ax=Assessment; Rx=Prescription; DDx=Differential diagnosis; Sx=Symptom

Improving Access to Psychological Therapies (IAPT)

Patients living in areas that do not offer community-based brain injury rehabilitation services may have been directed towards IAPT for their longer-term support needs. The stakeholders interviewed in this study suggested that IAPT services are not equipped to deal with the particular needs of individuals who have a brain injury, as they are mental health specialists. Therefore, it is likely that patients accessing IAPT following brain injury will not have their needs met (Figure 6.18).

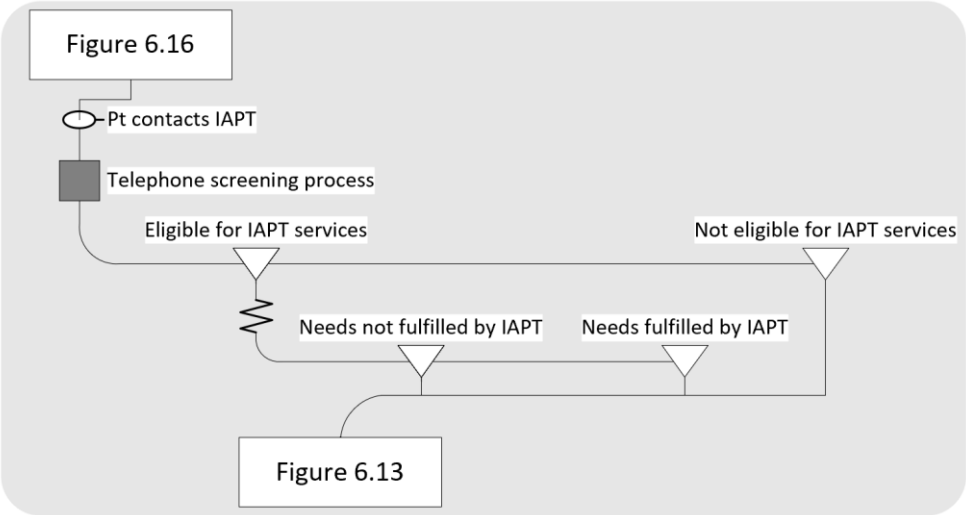


Figure 6.18. Detailed map: Improving Access to Psychological Therapies

Charities

The lack of community brain injury rehabilitation services and regional disparity in their availability may be, in part, filled by charity organisations. Headway proposes brain injury specific education, information, and peer support for people who have a brain injury and their families. Headway is generally known of specialist clinicians and the local group has built relationships in the University Hospital Coventry and Warwickshire Trust to contact patients early following their brain injury. Currently Headway has access to patients in the neurosurgery and neurosciences wards. Providing patients with information about Headway early on may prompt them to reach out for support in later stages of recovery. Clinicians in the brain injury clinic and GPs may also signpost patients to Headway when they perceive the it may help patients in their recovery, and particularly if appropriate community services are not available (Figure 6.19).

Headway in turn can direct patients toward other charity organisations, such as Mind UK, for people who may be experiencing specific psychological distress as a consequence of

their brain injury or the impact it has had on their life and the life of those around them (Figure 6.20).

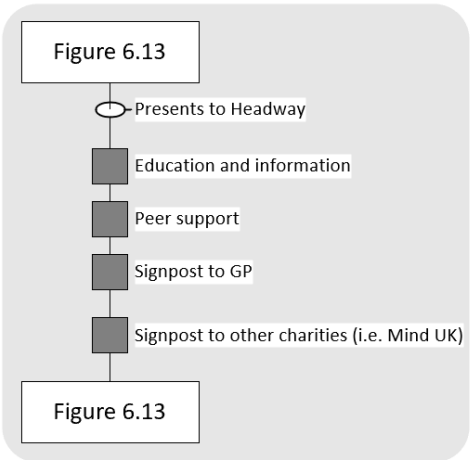


Figure 6.19. Detailed map: Headway

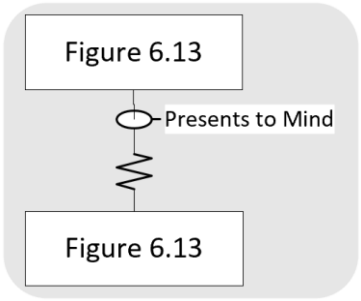


Figure 6.20. Detailed map: Mind

THEMATIC ANALYSIS

In addition to RAD modelling of the patient care routes, the interviews were analysed thematically to explore the perspectives of clinical and non-clinical stakeholders on the state of care for people with persisting symptoms following uncomplicated mTBI.

Four major themes emerged from the data. The first was 'heterogeneity' and related to the high variation between patients, injuries, and recovery trajectories. This theme also applied to the unequal distribution and availability of services in different geographical area. The second theme was 'fragmented care' and emerged from discussions around the lack of overarching pathway between acute and community-based care, as well as the difficulties for patients with milder TBIs to access specialist coordinated multidisciplinary care. The third theme, 'consequences', related to the impact of both heterogeneity and fragmented care and the relationship between them on the care and prognosis of people with P-TBI-S. The last theme, 'alternative approaches', resulted from discussions around ways to improve care for people with P-TBI-S.

Heterogeneity

The theme of 'heterogeneity' ran through multiple layers, including patient and injury characteristics, and service provision.

Patient characteristics

The patient population was described as variable in age, socio-economic background, and attitudes towards TBI and TBI care. Two core groups of patients admitted to hospital for TBI stood out: people presenting following a fall due to intoxication, and younger people who had sustained injuries following Road Traffic Collisions. The participants noted however that not all patients with TBI were admitted to hospital, and that indeed may not present to A&E at all. One participant noted that the reported increased incidence of TBI amongst the elderly population was not reflected in inpatient rehabilitation admissions for TBI. It is possible that TBI in these patients is not as easily detectable as other patient groups, because they may end up on wards that are not specialised in brain injury upon admission to hospital, particularly when they present with co-morbidities. Similarly, elderly patients presenting to their GP with cognitive or memory complaints and a history of TBI may be misdirected towards memory clinics because of higher age-related diagnostic uncertainty (i.e. dementia).

> *"I suppose the worry, clinically, when you got an older person post concussion who comes and complains of probably principally memory problems-- well they often complain of fatigue as well, although that's easier to manage. But when they start complaining of memory*

problems, particularly in that old age group, that's really hard because you start to get a lot of diagnostic uncertainty." (GP)

"If I think it's acceptable within the scope of a brain injury, and it is just normal and that it will take time, then I'm happy to deal with that. If I think that there is diagnostic uncertainty like dementia, I'll point the referral that I'm gonna make towards the service that I think it is. So if I think it's dementia, then I'll refer to the old age psych." (GP)

Age was also important in considering the patients' ability to return to the community successfully following TBI, with elderly patients potentially having a lower threshold for return to independent functioning after a hospital admission.

"Because often people who are just about coping, elderly people that are just coping, it's then one hospital admission that is the decompensation. It means that they can no longer return." (Rehabilitation consultant)

The patients' socio-economic situations were also seen as important in predicting or explaining persisting difficulties following TBI. Patients with less stable social networks and precarious accommodation and work situation were thought to be more likely to struggle with both persisting symptoms and access to care.

"Well I suspect the things that are protective […] will come down to social networks" (Rehabilitation consultant)

"And there's patients where you can just look on—and they're the ones who don't come back to clinic either because they're alcohol dependent, or the effects of the traumatic brain injury, or often they're homeless—and then you look and see that the clinical appointments have been sent to a homeless shelter." (Rehabilitation consultant)

The patient's postcode was also seen as a potential barrier to access to care, because the provision of services in different areas, even geographically adjacent, varies widely.

"Well, it's area specific, isn't it? North and South Warwickshire don't have Community Neuro Teams that are as responsible and are as skilled as [the Coventry] CNRT. Nowhere has voc[ational] rehab. We don't have a spasticity clinic within this area, so we refer out to Birmingham, but that's only if they can make it all the way to Selly Oak. If they can't make it to Selly Oak, they fall in a gap, we don't do botox as outpatients. In terms of what - but then the grass is always greener

on the other side, other services have other problems. So if there's some things we do well, other places don't and vice versa." (Physiotherapist)

Injury characteristics

Initial injury characteristics were also seen as an important factor of access to care. Patients with obvious and isolated neurological involvement are likely to be admitted directly onto the neurosurgery or neurosciences wards. Patients presenting with polytrauma however may be admitted onto other wards, such as the trauma and orthopaedic or general surgery wards. This can lead to missed diagnosis of TBI, and particularly of mTBI, as subtle cognitive and emotional deficits are not typically screened for in these settings.

> *"So they're people that have got sort of polytrauma, or significant trauma, and very often they've got a head injury. But their orthopaedic injuries take precedent." (Occupational therapist)*

In later stages of care, comorbid injuries may also delay access to neuropsychological care for patients with mTBI, as they may prioritize physical signs of injury. Co-morbid injuries also impact patients' attitudes about their care and care needs. Multiple clinicians suggested that patients may be resistant to psychological care until other (physical) symptoms have been addressed.

> *"I think sometimes if you try to get in there too soon, they're like 'no, no, I've just gotta do my physio, and everything will be okay'. And it's almost like they've gotta go through that process and then go, hit that 'oh shit, I see what you mean now'." (Clinical psychologist)*

An added difficulty is that patients may not acknowledge their need for care, which may be a direct consequence of the lack of insight and other cognitive difficulties brought about by the brain injury itself.

> *"Her husband fell off a ladder, hit his head, was never hospitalised. He went to A&E, was never hospitalised, but to cut a long story short, their relationship broke up because he said 'I haven't got a problem, the problem lies with you'. And it was all frontal damage, so personality changes. And he wouldn't accept the fact that there- he was the problem or he had a problem." (Occupational therapist)*

Service provision

While patient and injury characteristics impact the level of care needs, the availability and accessibility of appropriate services is important when evaluating care pathways. The

interviewees pointed out not only the paucity of appropriate services for people with milder isolated TBIs, but also the variability in provision and accessibility between different, although neighbouring, geographical areas.

> *"Well it's all variable from one place to the next. If you have your head injury in Leamington, there's nothing. If you have your head injury in Coventry, there's a least something." (Rehabilitation consultant)*

Fragmented care

Longer-term care for P-TBI-S was viewed as highly fragmented with no single defined pathway of care. Generally, patients with a more severe TBI or TBI with co-morbid injuries will have access to some level of multi-disciplinary rehabilitation services on an inpatient or outpatient basis depending on their level of needs and availability of services in their local area. Patients with a milder isolated TBI however were thought to be unlikely to receive an early referral for further support, least of all with multidisciplinary input. For this population, their access to further care is dependent on the nature of symptoms, the availability of services and the referral capabilities of the clinician they present to with persisting symptoms. While patients admitted onto the neurosurgery and/or neurosciences ward get referred for follow-up with a rehabilitation consultant, those who get discharged from A&E or indeed do not present for emergency care following their injury must go through their GP for further care.

In both cases, patients who do not have apparent multidisciplinary needs are unlikely to access specialist services, most of which hold multidisciplinary needs as a strict admission criterion, and they may be referred to non-specialist single discipline services.

It was noted however that post TBI symptoms may emerge gradually, meaning that a patient may need to access different services in a sequence. Patients presenting to their GP rather than to a rehabilitation consultant may have multidisciplinary needs, yet the GP may not be able to refer them for specialist multidisciplinary rehabilitation, therefore leading patients to accessing multiple non-coordinated non-specialist services simultaneously.

Services gaps

The fragmentation of care for people with P-TBI-S leads to gaps in service provision and access, particularly in longer-term, community-based settings.

Provision gaps

This lack of services was clear in the RAD mapping, particularly for the 'walking wounded' population, who do not need intensive multi-disciplinary inpatient care, and therefore are not eligible for referral into rehabilitation services. This creates referral loops between GPs,

neurologists and rehabilitation consultants, and creates unease with clinicians who have to balance their duty to support patients with their role in mitigate pressures on specialist services.

> *"And I suppose I've seen it as my role in primary care to not overburden the TBI services for these people on account of the fact that the presumption is that there might not be much that they can do for them or for their fatigue." (GP)*

> *"So they [the patient]'re not psychiatry, they're not neurology, and they're not neuropsychology, they're not psychotherapy. So they fall between all of these services. But yet, it's the second most common in outpatient clinic, it's the second most common presentation in neurology. So the first one is headache at 19% of outpatient consultations, the second at 16% is consultation around some form of functional neurological disorder. And mild TBI, in my view, is a tiny subset of that." (Clinical neuropsychologist)*

Vocational rehabilitation was also highlighted as a major service gap, which extended beyond this specific patient group.

> *"I mean the gap we do sit in is we have no vocational rehab. […] So we try and fudge the vocational rehab with the therapists you go to. So like CNRT would do vocational rehab and things like that, or they try to, but it's tough. […] Nowhere has voc rehab." (Physiotherapist)*

This patient group is however largely made up of working age younger people who would particularly benefit from vocational rehabilitation.

> *"It's one of the big things I'm looking at with my younger guys and my younger girls, is while I'm discharging, actually these people were career-driven and or they had good careers, and actually, yes I'm discharging them and we might be meeting their physical needs, and we might have addressed their cognitive needs but what about vocational needs? They want, that person normally wants to be a highly functioning member of society, and they want to be returning to work because that is part of who they are, and yet, that isn't offered." (Physiotherapist)*

This lack of vocational rehabilitation services used to be somewhat addressed by the charitable sector, through which access to courses at Warwickshire college was available to

people with brain injury. This offer was initially free, later for a fee, before finally getting withdrawn. This has left a significant gap for vocational support for people with brain injuries.

> *"Warwickshire College used to run courses specifically for people who'd had brain injuries […] they used to run: English, Maths, pottery, art, computer, rebuilding skills" (Headway representative)*

Access gaps

Difficulty in access to care was also highlighted. The CNRT was viewed as the rehabilitation service most adapted to people with P-TBI-S following a milder injury. Referrals to the CNRT however are not available for patients already in the community setting. As such, patients with P-TBI-S who were not admitted onto wards and demonstrated a need for CNRT input at discharge from inpatient care will not be able to access the service.

Inefficient use of resources

Oversubscribed services

The lack of coordinated care pathways coupled with the large span of services that may be accessed by patients across levels of care and sectors leads to inefficiencies in both service use and communication of information.

For patients experiencing P-TBI-S once they are back in the community, the primary route of access back into care is through their GP. GPs, who are not specialist in brain injury, have variable understanding of TBI.

> *"What does TBI mean to GPs I suppose is a good question. And I suppose for me, the gut feeling is for it to be labelled TBI, it would need to be sort of serious in some way or to have long lasting consequences, or more than someone who's just sort of just had a RTA [Road Traffic Accident], a minor RTA and bumped their head during that time. So I think it would be [interesting to] look at what people are coding, where's the cross over between minor and major head injury and TBI. […] For me it would be separate. But yeah, I'm not an expert in neurology or in brain injury, but yeah my feeling on that would be that concussion is the mildest end and concussion is-- you know a mild degree of concussion is normal after a head injury. But for me that wouldn't constitute traumatic brain injury." (GP)*

Moreover, patient records accessible to GPs may have relatively little information about the patients' brain injury assessed at A&E. Finally, referral options for TBI rehabilitation for GPs

are limited. Hence, it may be difficult for patients with P-TBI-S to be referred towards appropriate services. The GP interviewed noted that they did not have information about referral pathways for this patient population.

> *"When I was coming for the interview, the first thing I did was do what I always do when I'm unsure about a referral system or pathway, and that is go to something called the GP Gateway. […] And the problem is when I have no idea about a referral pathway, that's probably because there isn't one. So what happened when I typed 'traumatic' 'TBI' 'brain' or whatever into the gateway, nothing came up." (GP)*

Patients exhibiting obvious neurological signs are referred to a neurologist, although typical P-TBI-S is typically not associated with such signs. The lack of alternative referral options may however lead to GPs referring patients with P-TBI-S to neurology clinics. This sole but inappropriate referral option therefore leads to a looping around of patients between their GP and neurology clinics.

> *"if you look at the data about the GP access, they're just constantly going their GPs, having more and more medication, being referred to neurology, who will refer them back to the GPs, and they're just bouncing between the two." (Clinical neuropsychologist)*

> *"When people come to us and say 'I'm really struggling with this, where can I access support?', we just have to say 'you have to go back to your GP' on the basis that they know what to do" (Headway representative)*

This reliance on GPs to identify patients with P-TBI-S and address their care needs without specialist knowledge may also lead to inappropriate management if they are not aware of services available or have the time to make enquiries with specialist colleagues.

> *"We spoke about the sleep problem. One of the ways to re-establish a circadian rhythm is to use melatonin as well as a sleeping pill. The GPs sometimes resist the prescription of melatonin, right? So you end up having to prescribe it yourself, right? And at other times you end - what's called a shared protocol agreement - you send them the shared protocol agreement, so that they carry on with the medication, but some GPs particularly in certain general practices, they even refuse prescribing it. In spite of you explaining to them why the prescription was given. […] Some of the behaviour problems, and funnily enough there has been a review recently of the medical treatment required*

antipsychotics, like olanzopine or quetiapine, they refuse prescribing it because of their lack of awareness of what brain injury can be treated with. Not every GP has gone and read the most recent articles about treatment of neurobehavioural problems after brain injury. So they find it odd that you're prescribing them antipsychotics or an anti-epileptic for somebody who doesn't have epilepsy." (Rehabilitation consultant)

"you probably never find out about the ones that just discontinue the prescription. But I occasionally get letters, particularly for things like—well, I don't know, my practice is always to give a duration or a plan for how long people should be on it, if it's a brain injury specific medication. But I've had letters from GPs from other patients, questioning things like duration of sleeping tablets, and duration of neuropathic painkillers, and… So some GPs do think about it and think to ask." (Rehabilitation consultant)

"Occasionally we'd get a flurry of referrals from the same GP which makes you think they've discovered us for the first time" (Rehabilitation consultant)

Whether seen in a follow-up brain injury clinic or by a GP, people with P-TBI-S without multidisciplinary needs are unlikely to access specialist services. At GP level, a lack of understanding of TBI and its consequences coupled with few referral options constitute a significant barrier to access to further care for patients. The limited referral options are also considerable for people presenting to the TBI clinic. In both cases, initial management consists of education and reassurance, support for patient self-management and specific symptomatic management.

Underused services

The current offer for consultation in TBI clinics is also highly inefficient, as the non-attendance rate is high.

"It's not been unusual for a large percentage of them not to turn up. And when they're given hour-long clinic slots to do all of the cognitive screening and all the brain injury education, a morning clinic can be a complete waste of time. You might not get any patients turning up." (Rehabilitation consultant)

Consequences

Stretched services in acute care

For patients admitted onto wards, the lack of beds in appropriate rehabilitation settings leads to significant bottlenecks, which creates pressures in terms of patient flow, and lead to conflict between different HCPs.

> *"The problem we have in the acute sector, and particularly with neurosurgeons... They're quite egotistical and fair enough, they've done their bit, their treatment for that patient, so why are [the patients] in their acute bed blocking flow? And it's getting that message across, that 'yes they look fine, but I'm telling you they're not'. […] So flow in the hospital setting is the big push. Particularly for the mild head injuries." (Occupational therapist)*

The pressures on acute care are also linked to staffing issues, particularly of brain injury specialist therapists who often work across multiple wards and may be called for consultation in other parts of the hospital. Low staffing leads to prioritisation of patient assessment and management that is unfavourable to patients with milder injuries.

> *"So if we had someone that came in with very mild frontal contusions, something like that, we would want to try and pick them up, cause we'd want to assess their cognition. So a physio might not pick them up because we're not too worried theoretically unless something is flagged by the nurses, but the OTs would want to try and pick them up. Just, it just depends on capacity and staff. There's one OT that covers the entire ward, so if she's on leave we get cover from other wards, but they're - they rely on us as therapists, as physios, to try and flag them, and if we're a little bit slower at flagging, we might miss stuff, we might miss patients. And also without that specific occupational therapy knowledge, we can miss them" (Physiotherapist)*

Stretched services in inpatient and community-based outpatient care settings

The under-resourcing of services is also significant in inpatient and community-based outpatient settings, which have significant waiting lists and increasingly limiting admission criteria in order to prioritise patients with more severe and complex needs.

> *"We've got quite long waiting lists, I don't know off the top of my head, so I'd say between 12 and 20 weeks for someone to be seen, which isn't that bad because I know there's other areas in the country where their outpatient waiting list is 2 years." (Clinical psychologist)*

"I suppose the wait [for CNRT referral] is the concern as well, so you're looking at sort of 12+ weeks" (Occupational therapist)

"We have a community neurology team, but their condition for admission is to take any patients that is from the hospital. They wouldn't accept a patient who's already in the community for rehabilitation" (Rehabilitation consultant)

"Our day unit here is a bit like the Hitchman day unit at CERU [Central England Rehabilitation Unit], but I know CERU changed their criteria. Before they would accept pretty much anybody - I'm sure it wasn't quite like that, but I know that in the last couple of years they've tightened it up so [only] someone [who] needs to have access to two disciplines [will be admitted]." (Clinical psychologist)

The limitations imposed on patient care by staffing and bed shortages across the care system lead to clinicians having to find roundabout ways of getting their patients to access the services they need. This necessitates a good understanding not only of TBI, its consequences and its prognosis, but also of the care system and loopholes that can be exploited.

"Well you end up either referring them to non-specialist services. Say somebody comes in and they are cognitively well but say they have a weakness on one side or something like that, or to be honest with you, you try and twist it around so they need more than one discipline. Well, that's the truth isn't it? That's the truth. Say if they are physically, have some physical weakness, you try and say that please look at that functionality because of that weakness. When I say "twist it around", you're not saying something that's not true, something that has not been a priority in your mind, so you start digging in your mind if you like, how can I get this patient to have the best outcome?" (Rehabilitation consultant)

"So I had a patient from that area, but they'd come here for their acute inpatient treatment, and although I was gonna refer them to their local service, because it was nearer for them, saves them an hour drive, when I found out those waiting lists, they waited a little bit of time here, did the assessment, got all the information, got some recommendations and they've gone on to get on with their life,

whereas they would still be sitting on the waiting list waiting for their local service." (Clinical psychologist)

"It's far easier to withdraw a referral than it is to put one in last minute because of that wait. All I'm gonna do if I withdraw a referral is I'm gonna free up a slot for another patient that's due to go home. Whereas if I'm putting it in last minute, what I'm doing is completely clogging up the entire service and delaying our discharge. […] We might try and fill the gap a little bit with outpatient physio in the WISDEM building something like that. So we might try and fill the gap a little bit if we can, but their waiting list has gone up as well, they've got about a 10 or 11 week wait. So we will try and be as creative as we can, but it depends on what services are available." (Physiotherapist)

Patients with unmet needs

Low access to care for people with P-TBI-S, whether due to low patient motivation, lack of services or difficulties in access, heightens the risk of patients falling into a 'spiral of descent'.

"So the spiral that we talk about, predisposes to job loss, depression, and they end up socially isolated because their family breaks down and they lose their job and then they start drinking and then they get another TBI." (Rehabilitation consultant)

The lack of continued coordinated care also puts the onus on the patient to seek help. As such, it's likely that it leads to self-selection able and motivated patients with a sufficient level of insight into their difficulties.

"So I think that it's always the case that the ones who often, often the ones who do come back into the system or the ones that remain into the system, are the ones in least need of the support" (Rehabilitation consultant)

"You're always preaching to the converted, aren't you? So those that are more willing to take on that information, they're gonna seek help anyway, aren't they?" (Occupational therapist)

Alternative approaches

The current approach to management of P-TBI-S, particularly for people who have had a milder TBI, is generally poor. These patients may be increasing pressure on services that are

either not designed or not sufficiently resourced to meet their needs, or they may be left completely uncared for in the community.

Education and reassurance

There was general agreement that the primary intervention for people with milder TBIs is education and reassurance. Questions of timing, quantity and means of information delivery were brought up. Post-injury symptoms are fairly typical for some time following injury and should disappear on their own.

> *"And to some extent that it is normal [to experience symptoms] for certainly some months post-concussion" (GP)*

Patients are typically informed of this early on in their care journey. Some interviewees found that too much information about risks of persisting symptoms may be aggravating.

> *"There's the question of which people is it useful to say useful to say that to, and which people is it not helpful to say that to. So in terms of awareness, it could be useful for everybody to be aware that [persisting symptoms are] a possibility. In terms of emotional responses and avoiding self-fulfilling prophecies where the perceived message of a poor prognosis then encourages a poor prognosis…" (Rehabilitation consultant)*

Excess early information could also impede patients' openness to clinical expertise, and thus complicate management approaches.

> *"The easier to manage [are patients] not knowing [anything about post brain injury symptoms]. Well it depends if they're not knowing because they've got a lack of insight, that's really difficult because whatever you say to them they're like 'No, no, it's not brain injury. No it's not anything to do with that. No if you worded the question differently then I'd be fine. If the sun was shining in a different direction then I'd be able to do it'. So if it's on that scale, but if it's just they're totally naive and thought 'I was discharged from hospital and I thought I was fine, but something's not right', that's a good place to start with, cause they're open to information, they know what they're struggling with, and we can explain that to them, that's good. But then you get people at the other extreme end where they be 'I got executive problems, and my attentional difficulties are this, this, this' and they're not listening to actually that 'hang on, you are good at this, and it's probably not this, but it could be this'. But they've Googled everything,*

they know everything and they're on a mission to kind of fight. That could be problematic." (Clinical psychologist)

Integrated brain injury service with multiple referral routes

The current system largely relies on patients receiving, integrating, and acting upon information about brain injury given to them at early stages of care. Once in the community, their access or re-access to care is largely mediated by their GP, and a rehabilitation consultant for patients with follow-up appointments to the TBI clinic. In these settings, management mainly consists of education and reassure, and may involve some symptomatic management. The general consensus among the interviewees however was that patients with persisting symptoms are not well cared for in the current system, because it may well identify some patients with needs, but does not have the service offer to address those needs.

"And there's also, unless you get everything set up, it's something you can't do by halves, so it couldn't be like the current setup where one consultant sits in clinic and sees people and tells them stuff, because then you get stuck with people. Unless you've got a way to provide the help that they need and have that built into the clinic…" (Rehabilitation consultant)

"In a lot of cases, whatever you put it, something is gonna be better than nothing. But there might be a critical mass that's required for anything to be effective. So it might be that something isn't better than nothing, until you get to a certain level" (Rehabilitation consultant)

One interviewee highlighted that a more comprehensive approach is used in other parts of the country, such as Gloucester. The Gloucestershire Hospitals NHS Foundation Trust runs a clinical neuropsychologist-run mild head injury clinic which GPs, A&E and other inpatient hospital departments can refer patients into. Patients can also self-refer into the service. The mild head injury clinic offers assessment and advice, and offers monthly clinics with a physiotherapist and clinical psychologist. The Trust also has a brain injury group facilitated by a clinical psychologist and an occupational therapist and primarily aimed at people with persisting symptoms. This group runs over 6 sessions covering various aspects of brain injury symptoms and offers input from the local back-to-work coordinator.

DISCUSSION

SUMMARY OF RESULTS

This study aimed at exploring care pathways and journeys for people with persisting symptoms following TBI in Coventry and South Warwickshire. A two-fold analysis of interviews with clinical and healthcare support stakeholders showed there is a clear break in care routes between acute and community settings. Patients in acute care benefit from largely well-defined pathways and access to care irrespective of their postcode. Once discharged from acute care however, there is no defined pathway and care journeys are vague, variable, and highly dependent on service availability and accessibility, and clinicians' awareness of those services.

Patients, their injuries, and their recovery trajectories are highly heterogeneous, which suggests that proposing a single care pathway would not only be difficult but may actually not be appropriate. Difficulties in proposing one-size-fits-all approaches to the care of people with P-TBI-S on grounds of such heterogeneity have been highlighted in the literature (Chapter 3). This is commonly pointed to as one of the main barriers facing the development of all-encompassing care guidelines for the management of people experiencing persisting symptoms following injury [3,6].

This lack of pre-determined care pathway leads to particularly fragmented care for this patient group, as highlighted in both the RAD mapping and the thematic analysis of the interviews. There are few services specifically designed for patients with P-TBI-S in community settings, particularly for those whose symptoms are confined to cognitive and emotional domains. The availability and accessibility of these services is also unequal between the different Trusts' and CCGs' catchment areas. The onus to access care services at this stage is largely on patients themselves if and when their symptoms persist beyond the typical recovery timeframe. As such, it is likely that patients who lack insight into difficulties brought by their injury and/or lack willingness and ability to seek support do not access further care even when they might benefit from it. Further barriers include accessibility and knowledge of referring clinicians, particularly GPs. This fragmentation takes the form of service gaps, both in terms of provision and access, and results in both underuse of dedicated services -in this case the outpatient TBI clinic- and oversubscription of less appropriate services, such as rehabilitation services designed for people with more complex injuries and multidisciplinary needs.

One of the consequences of this inadequate care provision is that this patient group puts strains on services that are not equipped to care for them. Ultimately, this results in a number of patients with unmet needs bouncing around the healthcare system, or

disengaging with healthcare services altogether, therefore preventing their successful return to their community.

There is a major care gap in the community setting for education and support. The evaluation of early head injury education material distributed to patients at discharge from A&E (Chapter 5) was found to be generally vague and minimizing of the risk of experiencing persisting symptoms post-injury. Results from interviews with HCPs suggest that early education further highlighting risks of developing persisting symptoms may lead to self-fulfilling prophecies for some patients. Literature on the effects of extensive early education for people with mild TBI is divided, some finding that early education is beneficial and others suggesting that it might lead to increased reporting of post-concussion symptoms [262]. It may be that further education should only be provided when symptoms do persist. Regardless of timing of education, identified needs should be addressed and the current system is not designed to do so.

The current care offer for TBI rehabilitation is not suited for those whose condition is not linear and predictable, as is the case for people with P-TBI-S. The RAD modelling and thematic analysis showed that patients who are admitted into acute care and present clear rehabilitation needs at the discharge point have access to rehabilitation services. Patients who are discharged home from the acute setting (either directly from A&E, or following an inpatient stay that did not result in referral for further rehabilitation) and have delayed P-TBI-S, represent an important challenge for the healthcare system. There is no clear route for them to get back onto a rehabilitation pathway. While re-access routes into rehabilitation pathways are a core feature of models (such as the slinky model[5]), in practice for this patient group in the local area, this was shown to be very limited.

An ideal, holistic service for patients with P-TBI-S group would combine education and therapies services and should be accessible on a self-referral basis. GPs, in their capacity as healthcare service gatekeepers in the community, should be aware of P-TBI-S and direct patients with P-TBI-S towards this integrated service.

STRENGTHS AND LIMITATIONS

This study combined a traditional qualitative healthcare research method and a more novel, engineering based approach. This allowed for a systematic mapping of pathways as well as depth and nuance brought by the thematic analysis of interview transcripts. Using a RAD modelling technique to map care routes on a broad scope, from acute to chronic and looking at the transition between sectors and services shed light on issues related to lack of care coordination. Looking at single services on the pathway, it is not evident that the needs of patient are unmet. Looking at the larger picture however, it become clear that there is

significant looping of care routes between the different services, and a clear break between acute and community-based services. The downside of applying a RAD methodology to such a large scope is the loss of detail in the decision-making processes that has potential to come through in more limited settings. Because of the nature of the data collection required for RAD mapping –lengthy qualitative interviews—it was not possible to capture the views of all stakeholders in each setting. An added difficulty beyond these technical constraints is the multiplicity of pathways beyond acute care and the variability in service availability, clinical expertise of TBI and the higher representation of specific subgroups of patients seeking further support (i.e. highly activated patients who are willing and able to seek support). In addition, the participants were asked to consider how they would manage patients with mTBI, who may be considered the least memorable. This could have contributed to some of the participants' uncertainty as to how they have historically managed such patients. However, when prompted about how they would manage a hypothetical mTBI patient, the stakeholders were able to provide information sufficient to allow for the mapping of care routes. In spite of these limitations, the current study presents the most detailed account of pathways of care across such a wide range of settings to date.

The use of thematic analysis alongside RAD allowed for the exploration of stakeholders' views on the reasons why pathways of care are the way they are, as well as gain perspectives on the desirability and feasibility of potential alternative services for this patient group.

This study aimed for both depth and breadth of information about the care of people with persisting symptoms following TBI. The mixed-methods approach used in this study consisted of lengthy interviews with a range of stakeholders, which was time-consuming for both the researcher and the participants. In light of the work pressures endured by clinical and support workers in the healthcare system, it is not surprising that recruitment was difficult. A&E staff and therapists from CNRT were identified as important stakeholders in the care pathways of the patient group of interest. Multiple attempts were made to contact and set up interviews with clinicians in these groups but were ultimately unsuccessful. Data emerging from the dataset however provided a level of understanding of the role of these professionals that was deemed sufficient in the context of this study. The patient group of interest comprises people with milder TBIs, who will therefore likely get discharged home from A&E, if they presented at all. In regard to the CNRT, concordant data from multiple interviewees suggested that patients with a diagnosis of mild TBI and subtle deficits were highly unlikely to be seen by the CNRT, which typically cares for people with more severe TBIs or other neurological conditions.

IMPLICATIONS FOR PRACTICE AND FUTURE RESEARCH

This study showed a need for a more holistic approach to care in the community setting for people with persisting symptoms following TBI. This comprehensive service should be accessible through clinician referral and through patient self-referral. Not all people who sustain a mild TBI will experience persisting symptoms, therefore it is not necessary that all patients identified in acute care with these types of injury be directed towards this service. This is in line with a study from Wade et al.[172] that showed that not all patients will require further healthcare input following injury. It is important however that this service is accessible to all patients experiencing persisting symptoms and should be set up in such a way that it captures patients with support needs beyond those who are sufficiently motivated to seek support in the way that the current system allows. A study by King et al.[116] suggested that it may be inevitable that some patients fall through the gaps of care even when seamless services are available, but the results showed that patients who sustain mild and moderate TBIs should be monitored for some time following injury to maximise chances of capturing those with support needs.

It appears that the problem with medium to long-term care for people with persisting symptoms following TBI is three-fold. Firstly, the current care offer is limited in that there are few services that are designed or equipped to care for this particular group of patients. Secondly, access to further care is limited to patients whose clinical team is knowledgeable about the subtleties of P-TBI-S, aware of available services and able to refer them. Finally, the system puts an onus on patients to seek care, rather than systematically follow them up to identify those who may benefit from additional support.

More work is needed to better identify people who experience P-TBI-S and understand their needs. This will allow for the development of appropriate services and ensure that they can reach all patients who may benefit from further care.

CONCLUSIONS

This chapter set out to explore the organisation of the local services involved in the care and support of people with TBI, with a particular focus on care pathways, care journeys, and services needed for the management of people with P-TBI-S. This study was guided by 3 research questions:

1. Are there local pathways for people with P-TBI-S?
2. What are the typical care journeys for people with mild TBI in the local area?
3. What should local care provision for this patient group look like?

The findings from this study showed that there are limited care pathways for people with P-TBI-S, with only patients admitted to hospital following A&E attendance benefitting from a follow-up appointment at a brain injury clinic. It was noted however that attendance to this clinic was poor, and that referral routes for patients presenting at clinic were limited because of the strict admission criteria for rehabilitation services. In particular, patients who do not present with multidisciplinary rehabilitation needs are unlikely to access specialist services, and their management is moderated through GPs. Management offered in primary care settings largely consists of education and reassurance, coupled with symptomatic management as needed. GPs may refer patients for whom there is diagnostic uncertainty to other services, such as memory clinics for older patients with cognitive difficulty. As a consequence, there are important re-access loops in patient care journeys, who may bounce around between neurology clinics and GP surgeries for example. Local care provision should include more services and increased access to existing services (such as the ability to refer patients to the CNRT from community settings). Moreover, more widespread self-management guidance should be available to patients at all stages along their journey to recovery.

In the next chapter, self-management for people with P-TBI-S will be explored in the context of a chronic care model, and through collaborative work with brain injury survivor to develop an appropriate and acceptable self-management platform.

PART III: The next step

The opening chapter showed that mild Traumatic Brain Injury (mTBI) does not necessarily spontaneously resolve within the couple of weeks that are considered to represent the typical recovery period. Firstly, people with TBI constitute a heterogeneous population. Secondly, not all TBIs are alike. Therefore, it is difficult to precisely predict recovery trajectories. Historically, mTBIs were considered self-limiting with excellent prognosis. Research now suggests that it may not be so straightforward.

Part I highlighted some of the reasons for the paucity of rehabilitation guidelines: few studies explore care pathways, and those that do carry methodological limitations that render generalisation of findings –and thus their translation into guidelines— difficult. The global overview of the literature (Chapter 3), combined with more detailed exploration of care reports (Chapter 4) however gave good indications as to what components should be included in a defined care pathway. These findings were used as the basis for the exploration of rehabilitation in England, and particularly in the West Midlands, conducted in part II.

In part II, the examination of Patient Information Leaflets (PILs) in Chapter 5 showed low levels of patient education regarding risk of experiencing persisting symptoms following TBI. It also highlighted the critical role of GPs in mediating access to further care for people with Post Traumatic Brain Injury Syndrome (P-TBI-S). Beyond this, signposting to other sources of support was poor and inconsistent. In Chapter 6, the broader care routes for people with TBI was explored, from acute to community-based care setting. This study showed a clear break in pathways in the transition from acute to community-based services. In line with findings from the analysis of PILs, this study confirmed the central role of GPs. It notably highlighted the paucity of community services for people with P-TBI-S, and the inconsistencies in service provision between Trust and Clinical Commissioning Group catchment areas. The thematic analysis of interviews highlighted the importance of clinicians' awareness and understanding of both P-TBI-S and services susceptible to support patients in addressing their needs. This study showed that resource-limitation of services often superseded patient needs in accessing care. Mapping of existing care pathways and current care routes through interviews with healthcare and support services stakeholders was successful, and further work is needed to input data on patients' access to the different care services thus identified. Interviewees highlighted a need for better patient education

at different stages of recovery, and enhanced access to P-TBI-S-specific rehabilitation services.

The care journeys of people with P-TBI-S are highly heterogeneous. People with obvious and multidisciplinary rehabilitation needs may be able to access rehabilitation care within the current structure of the care system, but those with more subtle impairments are largely left to their own devices to manage their impairments. The care approach for this patient population largely consists of self-management and symptomatic management provided by their GP. The patterns of access to services for these patients is unclear, but assessment of service provision in the local area suggests that people with P-TBI-S may be bouncing between different services which may not be adequately addressing their needs.

The aim of the work in part III was to propose a way to support self-management and appropriate re-access to healthcare services, and suggest new avenues to explore care journeys of people with P-TBI-S.

Part III consists of one piece (Chapter 7) of collaborative research with brain injury survivors addressing 2 research questions:

1. What features would be useful to people with P-TBI-S in a mobile app for self-management?
2. Would the use of this mobile app for research purposes be acceptable to people with P-TBI-S?

Chapter 7 combines alternative approaches to both care and research through a mobile app project co-developed with expert patients using a Patient and Public Involvement approach. The aim of this project was to create a dynamic mobile self-management platform for people with P-TBI-S to support them in their journey to recovery, and enable further research on their access to care and support services.

CHAPTER 7 – SELF-MANAGEMENT FOR P-TBI-S

In the previous chapter (Chapter 6), important gaps in the care provision for people with P-TBI-S were highlighted. Current management of this patient population relies on education and reassurance in an aim to promote self-management. However, findings from the study presented in Chapter 5 suggested that the level of information provided to people at risk of P-TBI-S is limited.

In this chapter, the concept of self-management for people with Traumatic Brain Injury (TBI) and more specifically those with Post Traumatic Brain Injury Syndrome (P-TBI-S) will be explored. The first stage of the development of a mobile app to support self-management, resulting from collaborative work with brain injury survivors is presented here.

Figure 7.1 highlights the place of this study within the broader structure of this thesis.

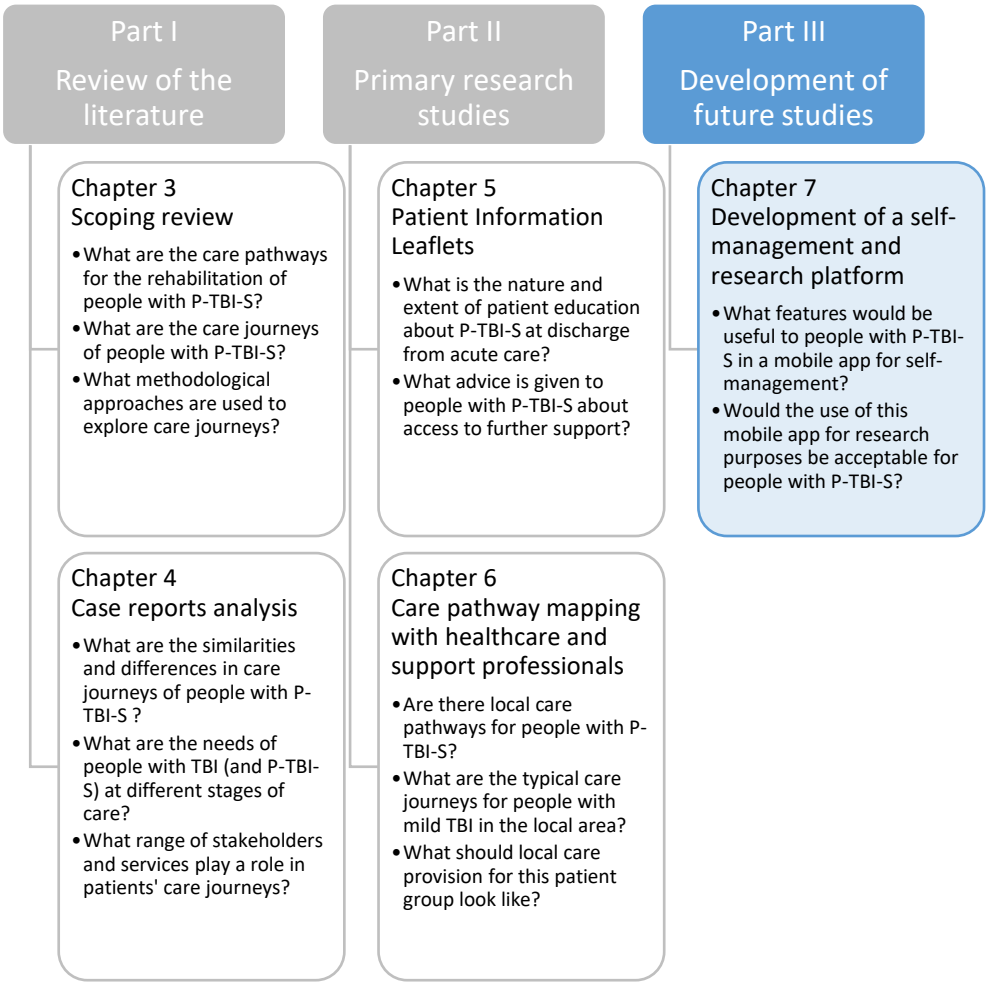


Figure 7.1. Chapter 7 within thesis structure

BACKGROUND

The review of the literature and exploration of local care processes have highlighted the lack of defined care pathways for the rehabilitation of people with Post Traumatic Brain Injury Syndrome (P-TBI-S). Although the current approach largely relies on patient self-management, the advice given to patients is minimal, vague and non-specific. Repeated access to services in the community suggest that this approach is inefficient.

In many respects, P-TBI-S can be considered a chronic condition. In particular, persisting symptoms can render re-integration into the community following Traumatic Brain Injury (TBI) difficult, because of ongoing, and often non-specific, symptoms that need to be managed.

CHRONIC CONDITIONS

Definition and care structure

Much like TBI and P-TBI-S, "chronic condition" has multiple denominations and variable definitions. Characteristics typically used to define a condition as "chronic" include: aetiology, duration, onset, pattern, prognosis, sequelae, diagnosis, severity and prevalence [263]. The majority of definitions still heavily rely on duration of condition to determine chronicity, and typically use 3 months as a cut-off [264]. In the context of healthcare, definitions and terminology are crucial because global healthcare policies will group conditions in categories. As such, failing to label a condition as "chronic" may impede development of appropriate support services, for lack of designated funding.

The 2014 NHS Five Year Forward View[265] as well as the 2019 Long Term Plan[94] both acknowledge the rise in numbers of people living with long-term conditions. They highlight the ambition of the NHS to empower patients by widening access to medical and care records, and better support them to manage their own health [265, p.12; 94, p.12, 93].

As discussed in Chapter 1, P-TBI-S can be conceptualised as a chronic condition, in that it can last for months to years, and can severely impact one's functioning. Consequently, people who experience P-TBI-S may require access to chronic care services. However, the review of the literature and studies on the local care provision for these people showed that this is currently not the case.

Challenges in chronic care

The difficulty in defining boundaries for chronic care resulting from the terminological variability is increased by the complex organisation of care for such conditions. Indeed, care for chronic conditions often involve a multidisciplinary team spanning both primary and specialist care settings.

Chronic conditions account for the overwhelming majority of healthcare costs [266,267], yet the limitations of current care systems in their capacity to deal with these conditions are substantial. Bodenheimer et al. [268] proposed that chronic conditions generally present in the following way: the acute symptoms caused by the underlying illness become priority concerns for the patients, therefore crowding out the less urgent underlying needs. It is not unlikely therefore, that much of the clinician-facing care will focus on addressing immediate acute symptoms, rather than exploring more complex and subtle underlying patterns of 'deficits'. For example, in a typical 10-minute consultation with a GP, the clinician may have time to review blood pressure and adjust medication, but not necessarily focus on the underlying cause of the high blood pressure. As such, the bulk of medical interactions for patients with chronic conditions are limited to addressing a sum of parts rather than the

whole of their condition. This idea is reinforced by the current care approach to P-TBI-S, which largely consists of symptom-specific assessment and management (Chapter 3).

However, by treating symptoms in isolation, this approach fails to acknowledge P-TBI-S as a chronic condition that calls for coordinated, organised care. Community care was originally envisioned as a specific therapeutic model, but has become the overflow solution to overrun long-term care services in need of a transitional care point to discharge patients to [269]. As such, community services are currently caring for people discharged from long-term care for whom specific transitional care settings would be better suited, and thereby are lacking resources to support the people for whom community services were originally designed for.

The Chronic Care Model (CCM)

The Chronic Care Model (CCM) was developed from the observed inadequacies of a system designed for acute rather than chronic care [268,270]. It emphasizes the importance of including non-physician personnel, including the patient themselves, to further participate in the management of chronic conditions [271]. The aim of the CCM is to bridge the gap between idealised care pathways and current practice in order to achieve better outcomes for patients [268]. Bodenheimer et al. identified 6 core factors that impact chronic care [268]. These components, and associated questions that can help assess the care provision are presented in Figure 7.2.

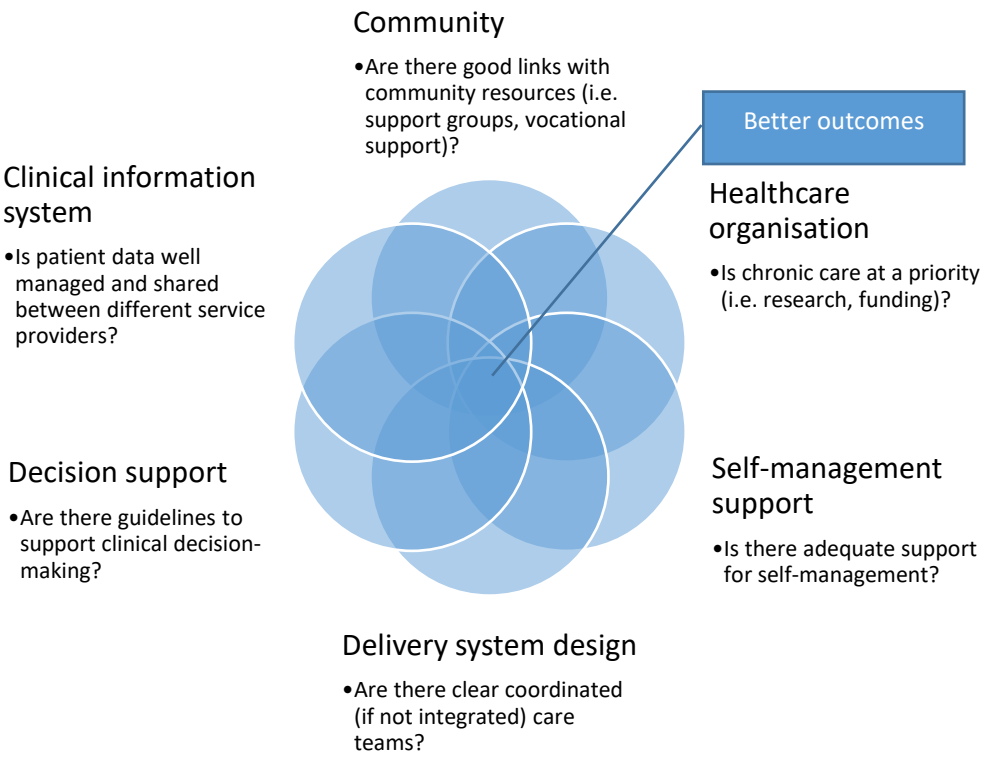


Figure 7.2. Chronic Care Model

(adapted from Bodenheimer et al. (2002) [268])

Studies presented in this thesis highlight different shortcomings of the current approach to P-TBI-S care when viewed in light of the CCM. An integration of the findings of the thesis with the CCM is presented in Table 7.1.

Table 7.1. Assessment of P-TBI-S care through a Chronic Care Model lens

CCM=Chronic Care Model; P-TBI-S=Post-Traumatic Brain Injury Syndrome; PIL=Patient Information Leaflet

CCM domain	Question	Assessment
Community	Are there good links with community resources for people with P-TBI-S?	**Chapter 5** – Signposting to community resources in PIL was limited. Although most highlighted GP as the point of contact should symptoms persist following TBI, few directed patients towards community support services accessible without clinician referral such as charities. **Chapter 6** – The exploration of pathways showed clear break between acute and community-based services. Access to further services was largely mediated by GPs or TBI clinic clinicians for patients with follow-up appointments following post-injury inpatient admission.
Healthcare organisation	Is chronic care for TBI at the top of the organisational agenda?	**Chapter 7 –** Along with work on prevention, the management of chronic conditions is one of the areas of development prioritised by the NHS. The Five Year Forward View presented different models of care aiming at a better coordination of primary care, community and hospital services [265]. This aim was also the first presented in the 2019 Long Term Plan [94].
Self-management support	Is there adequate self-management support for people with P-TBI-S?	**Chapter 6, Chapter 7 –** Supported self-management for people with P-TBI-S is insufficient.
Delivery system design	Are there clear, coordinated care teams for patients with P-TBI-S?	**Chapter 3** – Multidisciplinary care may be used for patients with P-TBI-S whose symptoms are refractory to initial treatment approaches. There is however insufficient evidence to recommend MDTs for all patients with P-TBI-S[10]. **Chapter 5** – Care for people with P-TBI-S is largely uncoordinated
Decision support	Are there guidelines to support clinical decision-making?	**Chapter 3 –** The scoping review showed that although a number of guidelines regarding the assessment and management of TBI exist, few are explicit in pathways of care for people with P-TBI-S.
Clinical information system	Is patient data well-managed and shared between different care providers?	**Chapter 5 –** Uncoordinated care for patients with P-TBI-S leads to miscommunications between clinicians in different settings

SELF-MANAGEMENT

The lack of sufficient support for patients experiencing negative long-term effects from a TBI raises questions about self-management for three main reasons. Firstly, the ways of identifying patients who need further support remains unclear. Not all patients with TBI will experience lasting symptoms that may necessitate further intervention. Even within the group that does, not all patients will access appropriate support services, if they seek support at all [77,203]. The variability of symptoms and their heterogeneous and multifactorial development patterns (i.e. the patterns in which the symptoms come about) render prediction of poor outcomes difficult (Chapter 1). Secondly, the multidisciplinary nature of potential support services implies significant investment in multiple care specialties. Because the nature of P-TBI-S is so variable, not all patients will need to support from the same specialties. Consequently, while a vast number of specialties may need to be involved in order to propose comprehensive care for the largest possible group of patients, the usage pattern will remain unpredictable. This means that commissioning resources specifically to address P-TBI-S and distributing them fairly around the different specialties would be difficult and likely wasteful. Finally, symptoms of P-TBI-S are non-specific. As such, it is likely that services that could support people in this group already exist, and low access is more due to lack of identification of appropriate services in a timely manner than to a lack of adequate provision. For all these reasons, it appears critical that patients themselves are provided with the tools to identify and address their own needs (which may include seeking clinical input).

This study focuses on the development of a self-management tool, and explores its potential in generating research data about care journeys on a large scale.

Definition, aim and scope

The term 'self-management' was coined by Thomas Creer in 1976 [272] and stems from the idea that patients should be active participants in their own health. Lorig et al. [273] argue that all people manage their own health, in the sense that their behaviour, whether healthy or unhealthy, cannot 'not' have an impact on their health. As such, they argue that the true question lies not in 'whether' patients manage their health, but rather 'how' they manage it. Therefore, the goal of self-management is to facilitate appropriate oversight of people's own health.

The CCM proposes that patients and their families are an integral part of the health care team in a patient-centred approach to care. Therefore, a core element of the CCM is that patients should have the skills, knowledge and motivation necessary to participate in their own care [274,275]. In 2004, Hibbard et al. [276] proposed a four-level standardized measure of activation: the Patient Activation Measure (PAM) (Figure 7.3).

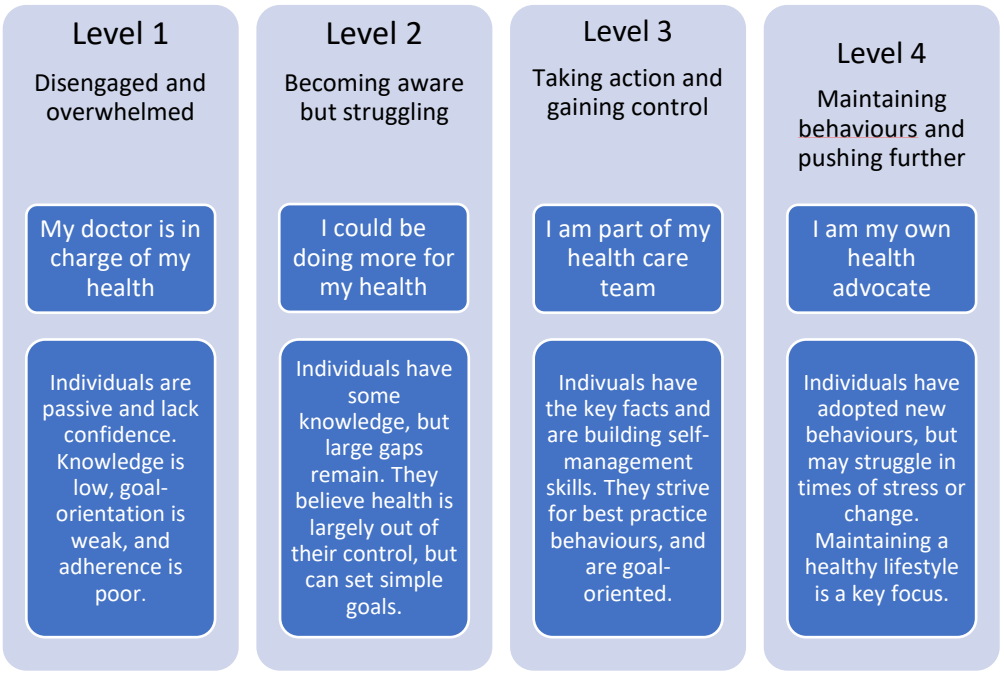


Figure 7.3. Levels of patient activation

(adapted from Insigna Health [277])

Building on their work on the PAM, Hibbard et al. developed a measure of clinicians' beliefs about patient self-management [278]. The clinicians generally embraced self-management as a way to enable patients to follow medical advice, but were less supportive of its role in increasing patient self-determination in terms of deciding whether they should seek clinical support or could manage their condition independently. Self-management however does not imply absence of medical oversight and should instead be viewed as a component of chronic care. This increasing focus on self-management aspects of care is in line with the broader paradigm shift in healthcare towards a more holistic, patient-centred approach [279]. Paterson highlighted the concept of individual outlook as an important factor of one's health [280]. It can be argued that empowering patients to take action towards better outcomes for their health condition is key to recovery. Work around patient activation suggests that increased involvement of individuals in choices around their own care leads to both better outcomes and more cost-efficient healthcare [281]. Taking responsibility for their own care also likely increases patients' adhesion to treatment plans, which is particularly important in chronic conditions.

In cases where health and social care support provision is inadequate, self-management should be approached carefully. Indeed, a criticism of unsupported self-management is that it assumes that the individual is largely responsible for their wellbeing, regardless of how unfavourable the social, political and economic context might be. Similarly to criticisms of

mindfulness, it can be argued that the push for self-management is a neoliberal individualist solution to a broader societal problem[282]. Thus, without questioning the socio-political factors leading to inequalities that contribute to the persistence of symptoms and difficulty with community re-integration, the patient is held responsible for their lack of resilience and/or failure to develop and apply appropriate coping strategies. Capitalist forces have not ignored the potential for self-management to become a source of profit. The plethora of health apps, often paired with tech devices (i.e. smart watches and fitness trackers), is a testament to this venture into reaping benefits from people's ill health. Commercial health services have also been taking advantage of gaps in healthcare in offering services bypassing clinical input which is potentially risky and may lead to poorer health outcomes [283-285].

Criticisms of self-management used in isolation, or as a complete replacement of appropriate medical oversight is valid. However, when used as initially theorised, as part of a complete care plan, self-management can be highly beneficial. In the context of P-TBI-S, care currently mostly consists of patient education, lifestyle adjustments and gradual return to normal activity as symptoms resolve. This can be supplemented by therapies and pharmacological interventions as a second line approach. In this context, strong supported self-management for P-TBI-S appears appropriate as it has potential to increase patient activation and reduce burdens on a healthcare system that is poorly suited to care for these patients (Chapter 6).

Features of self-management

Efficient self-management programmes comprise 5 key steps [273] (Figure 7.4). The first step to successful self-management is to define the problem. The second step is to generate various options to help resolve the problem. This is key to ensure that the patient is involved in the decision-making, and empowered to take responsibility in addressing issues. The third step is to identify and use appropriate available resources. The fourth step is to collaborate with the healthcare team. The fifth and final step is to take action. Within this, evaluating outcomes is also key.

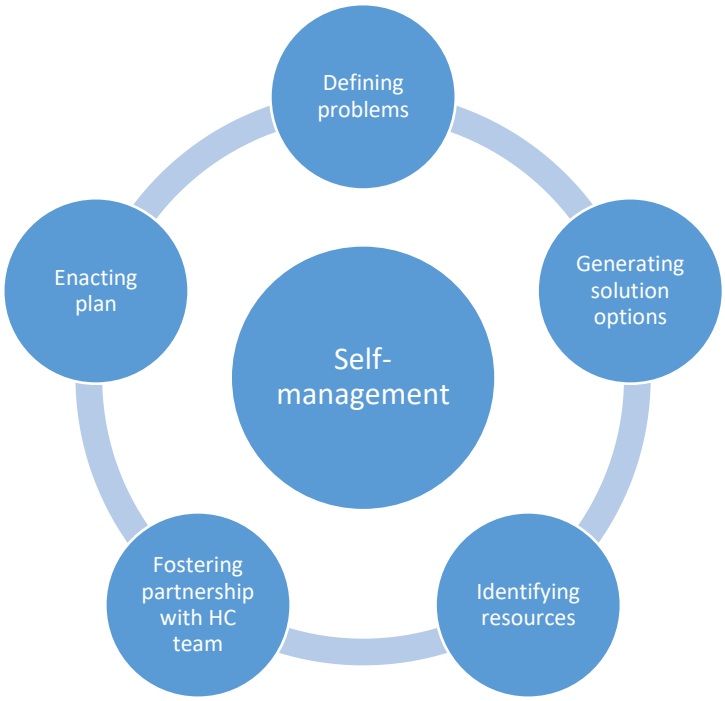


Figure 7.4. Features of self-management

HC=Health Care

This model of self-management is in line with current patient-centred approaches to healthcare, where patients ideas, concerns and expectations are taken into account to devise care plans [94].

RESEARCH OBJECTIVES

A number of people with P-TBI-S find themselves in the community with little or no support (Chapter 6). It is likely that this group would benefit from better and more accessible information about P-TBI-S and support options available to them to assist them in their journey to recovery (Chapter 5).

Exploration of the literature highlighted the paucity of information regarding access to care for people with P-TBI-S (Chapter 3). It appears however that these patients are accessing care services beyond the acute phase, in a way that is inefficient for the healthcare system, and unhelpful in addressing their needs (Chapter 4, Chapter 6).

The aim of this study was to work with expert patient to develop a mobile self-management platform for people with P-TBI-S to support them in their journey to recovery, and enable future research on their access to care and support services. Two research questions guided this study:

1. What feature would be useful to people with P-TBI-S in a mobile app for self-management?
2. Would the use of a mobile app for research purposes be acceptable to people with P-TBI-S?

METHODS

To ensure that the outputs of this project are relevant, and thus improve chances that it will be taken up by people with brain injury, this initial development stage was embedded in a Patient and Public Involvement (PPI) approach through collaborative work with expert patients.

The core principle of PPI is that research should be "carried out 'with' or 'by' members of the public rather that 'to', 'about' or 'for' them" [286].

As work presented in earlier chapters has shown, one of the difficulties of caring for people with P-TBI-S is that the onus to access services is largely on the patient themselves. The nature of P-TBI-S may leave patients unmotivated and/or unable to reach out for support when they need it. As the aim of this chapter is to produce a platform to assist people in finding relevant information and support in their recovery journey, it appears critical to anchor this development process in a PPI approach, to ensure the platform and associated research is both acceptable and relevant to patients.

Table 7.2 presents the adherence of this work against the GRIPP2 short form, a checklist designed to improve the transparency and quality of PPI research reporting [287].

Table 7.2. GRIPP2 short form

(adapted from Staniszewska et al., 2017 [287])

Section and topic	Item	Reported on page No
Aim	Report the aim of PPI in the study	224 - 225
Methods	Provide a clear description of the methods used for PPI in the study	225 - 227
Study results	Outcomes: report the results of PPI in the study, including both positive and negative outcomes	228 - 234
Discussion and conclusions	Outcomes: comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	237 - 239
Reflections/critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience	238 - 239, 251 (Chapter 8)

RECRUITMENT

Potential co-developers were identified at a local brain injury support group meeting organised by Headway West Midlands. The aim of the meeting was to present the research area and work conducted to date, and call for interest in co-developing a self-management platform for brain injury survivors. The paucity of services available for people with P-TBI-S within the healthcare system and resulting difficulties experienced by people with brain injury, such as accessing relevant information, were discussed. Information sheets (Appendix 7.1) and expression of interest forms (Appendix 7.2) were circulated. People who filled out the forms were then contacted, and asked about their preferred platform for the project (i.e. email, Facebook group, messaging app).

DATA COLLECTION AND ANALYSIS

The initial development stage, consisting of identifying core features of a self-management mobile app for brain injury survivors, was conducted on WhatsApp between January and April 2019.

Initially, the intention was to set up workshops where expert patients and the researcher could meet in person to discuss ideas and create app mock-ups. However, for practical reasons including finding an appropriate space and suitable times for meeting, the participants in the working group preferred conducting this work remotely on an

asynchronous basis, thus allowing for flexibility in timing of involvement. A joint decision was made to use WhatsApp as a platform as all members were already users of the app.

The chat was mostly informal following a quick introduction message posted by the researcher, which included the aim of the work which was “to discuss ideas that [would] eventually leave to the development of an app for brain injury survivors”. This was followed up by an initial prompt question: “what do you think should be in an app designed for brain injury survivors”. With the initial ideas generates, the researcher produced an initial app design, which was sent to the group for comments and further suggestions. These initial designs along with further discussion were used to generate refined app designs.

The different discussion points along with the app designs are presented in the results section.

RESULTS

Five Expert Patient (EP) co-developers, in addition to the researcher, were included in the group chat. Two main themes were discussed: firstly, the components of an ideal brain injury self-management app, and secondly, the potential for the app data to be used in research (Figure 7.5).

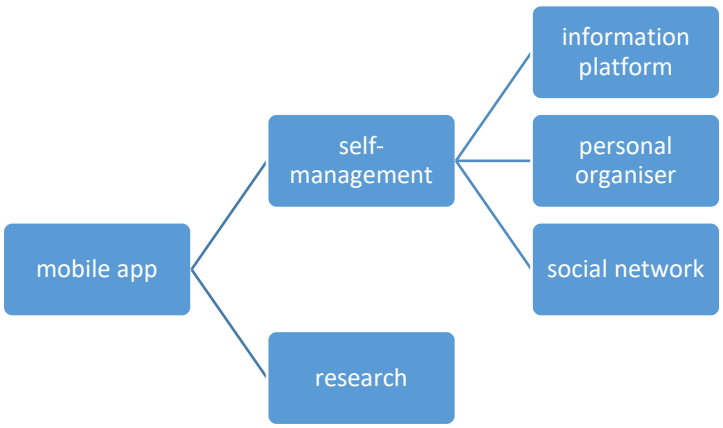


Figure 7.5. App components

APP COMPONENTS

In terms of app features, 3 core features were highlighted.

Firstly, the group felt the app should include an information platform. This was suggested to be not only useful for patients, who might not be able to 'take in' all information given to them by their medical team, but also as a way to inform families and friends.

> *"In the early stages of recovery, they [patients] need family or friends to know about these apps." (EP2)*

Secondly, there was a desire for multiple 'personal organiser' functions. A contact book was suggested, including contact details of appropriate clinicians, services, but also of support groups.

> *"[A list of] GPs and consultants. Personally, I see a lot of nurses and I can never find their numbers…" (EP1)*

> *"[It would be] very useful to have an index of facilities that are available […] broken down into sections […]: 'Social groups' […], 'Hospitals' etc." (EP3)*

> *"I like the idea of an index of facilities where you can find [support] groups and could also have details of counsellors that you could contact for help." (EP4)*

Another 'personal organiser' element was a symptom tracker, paired with an automated alert system that would send appropriate and timely information and signposting based on user input.

> *"[It would be useful to have] a personal action plan to follow if something isn't quite right healthwise." (EP1)*

Thirdly, there was a strong push for the inclusion of social networking features in the app. Patient experts often pointed out the importance of peer support, and the delay that they had faced between their initial injury and their first contact with support networks. They highlighted that support groups were seldom pointed out to them by clinical staff (or at time during which they were not receptive to that information), and that they often had to find out about these groups on their own.

> *"When I was in hospital, there were leaflets about Headway. Other things I had to find out myself and it's hard to find things." (EP1)*

Consequently, many of them only accessed these face-to-face support meetings months or years after their initial injury. Some attributed the delay in accessing these support groups to not feeling ready for face-to-face interaction in the early stages of recovery.

> *"[It took] 2 years before I had the confidence to leave the house." (EP2)*

The app should include a social element for brain injury survivors to connect with one another.

> *"Face-to-face [peer support] like Headway is best, but a forum/chat section [on the app] would be good too." (EP4)*

> *"Sometimes, in everyday life, people don't understand people who have had a brain injury and it is always good to have friends you can be in touch with who just totally understand you." (EP1)*

> *"When you are having a bad day, [there is] no need for explanation if people know and understand." (EP2)*

This discussion led to the creation of initial mock-ups (

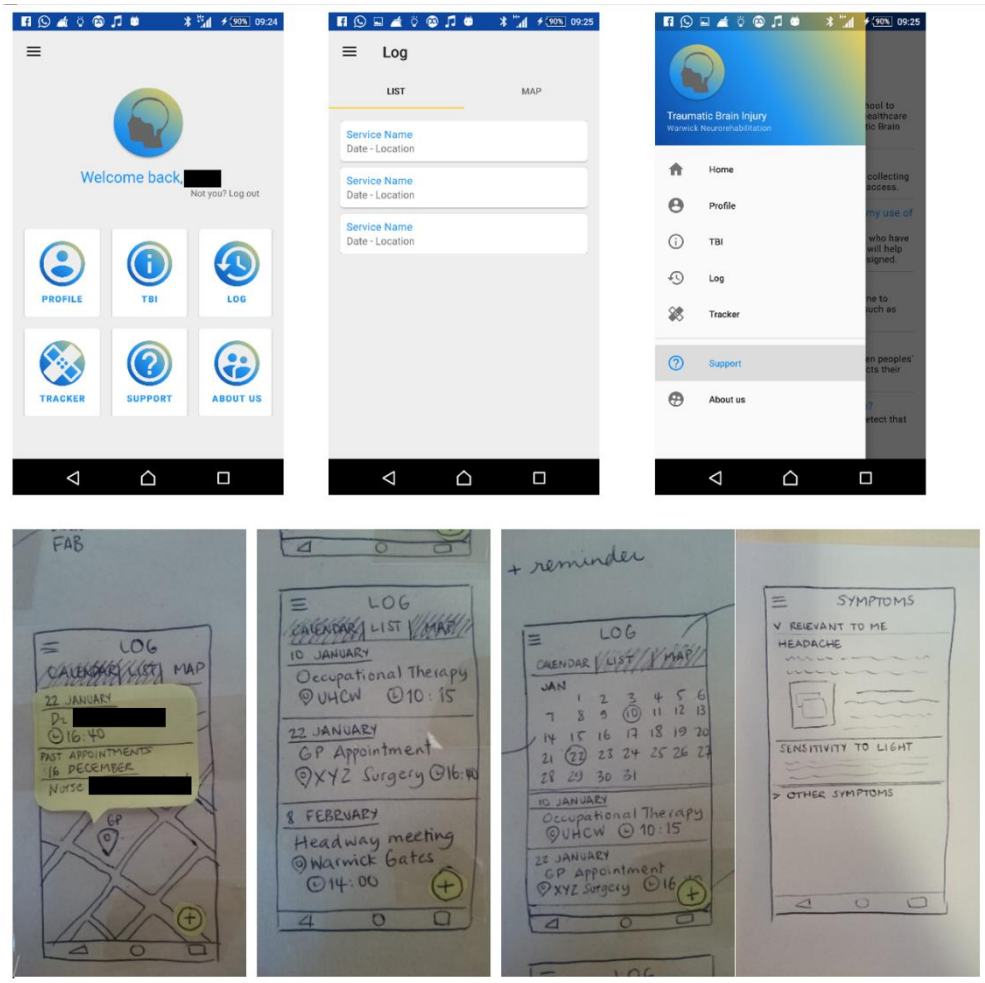


Figure 7.6), which were posted to the chat for feedback, following which the app design was refined (Figure 7.7).

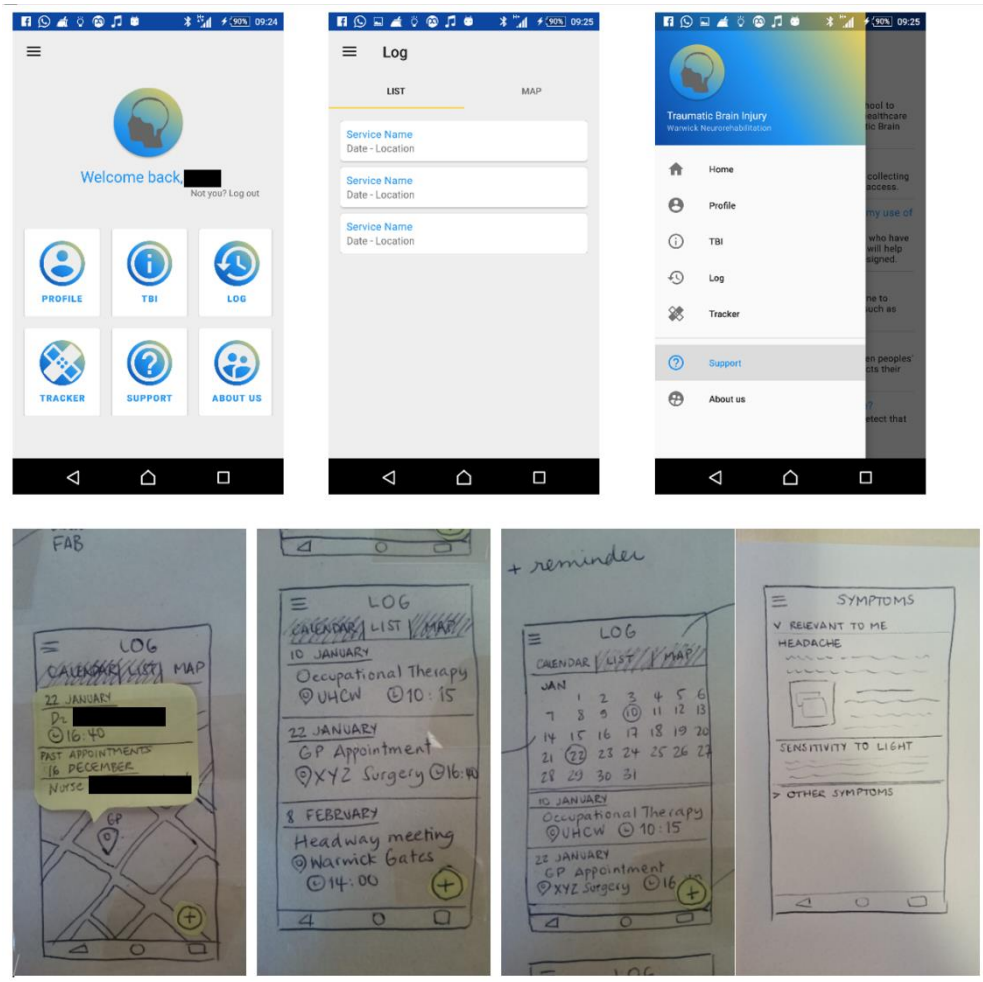


Figure 7.6. Initial app design

The top row of images shows the initial designs submitted to the group. The second row depicts some of the changes and additions suggested by the group.

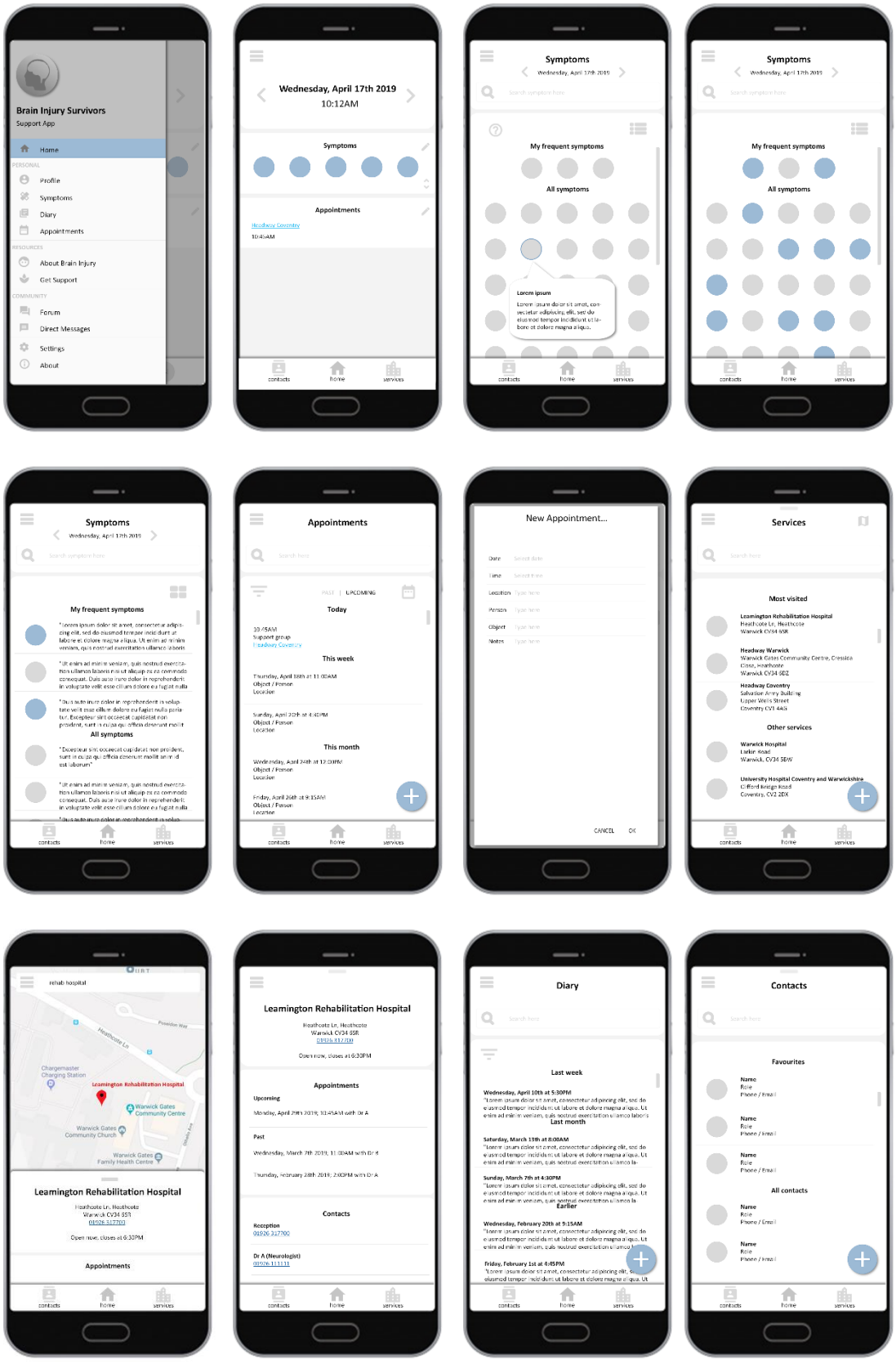


Figure 7.7. Refined app design

A digital design created from the initial designs, and the suggestions for changes and added features from the group

Throughout the discussion, two seemingly paradoxical ideas emerged. The first was a strong desire for the app to be multi-functional and represent a centralised information and self-management platform, and to be customisable to individual needs. The second was the desire for the app to be simple to use. Co-developers suggested that any app too difficult to navigate would discourage use. It was also pointed out that cognitive difficulties brought about by brain injury mean that this threshold for complexity can be lower than in the general public.

> *"There are so many complicated things to navigate in life with a brain injury […] it can be easy to feel overwhelmed." (EP1)*

> *"if it got too complicated, I would get in a bother and not use it" (EP1)*

An all-encompassing app design integrating the different features discussed earlier appealed to some, but others suggested that it might lead to unnecessary duplication of services offered by other apps. For those EPs, the self-management app should therefore allow for synchronisation with third-party apps, as any data entry duplication would be unnecessarily taxing. This was specifically in relation to the calendar and contacts features.

> *"[a sync option] would be very useful as I live by my current Google diary, so I would find it very hard to move to a new diary without this functionality" (EP3)*

RESEARCH ELEMENTS

It was generally difficult to shift the discussion to views on app data being gathered for research purposes. One member strongly suggested that they would prefer app data not to be shared.

> *"I would have [the research element] separate [from the self-management]. […] Sometimes it's hard to get away from all the medical things and I value privacy and having safe places and spaces." (EP1)*

> *"Medical professionals find me 'complex', medical researchers find me 'fascinating', but at the end of the day, I'm just [EP1] and just trying to live my life as best as I can" (EP1)*

Some EPs were more open to the idea of data being used for research, but all indicated that it would need to be very clear what data were being used for research and in what way.

In the end, the concept of 'data' in the context of this app seemed difficult to define, and discussions about the technicalities of information collection were difficult without a

working prototype. Team members suggested that a face-to-face meeting with a live presentation of an app prototype would be helpful in visualising which and in what way data may be shared for research.

DISCUSSION

SUMMARY OF RESULTS

At present, there is a gap in services that is leading to patients with P-TBI-S following uncomplicated TBI to largely fend from themselves. Because of the high potential for debilitating symptoms resulting from TBI to occur sometime after injury based on their fluctuating nature and variable contextual factors (Chapter 1), a number of patients with rehabilitation needs are falling through the gaps of the healthcare system (Chapter 6). Two options therefore present themselves: the first is that patients can find their way back to services as needed through existing channels (i.e. GP, brain injury clinics); the second is that they manage issues that can be managed without specialist input in a timely and appropriate manner relatively independently.

This PPI work explored the potential for both options to be mediated through a mobile application. The team found that a centralised platform about brain injury recovery would be useful. They highlighted that core features should revolve around information about brain injury and brain injury services; personal organiser components, and social networking elements. The group was more ambivalent about the data being used for research, although there was some indication that it was difficult to form an opinion on the matter without concrete examples.

This research presented in this thesis highlighted a gap in the service provision for people who do not meet the requirements for follow-up after acute assessment and diagnosis of mTBI. It is generally assumed that these people should be able to manage their post-injury symptoms at home.

One of the issues highlighted by the co-developers was that it was sometimes difficult to know how to move on after the initial injury. This suggests that post-injury patient activation may be low, as survivors lack the knowledge and confidence to engage in appropriate self-management [276] . Some solutions were offered by co-developers to increase their confidence in managing their symptoms, for example through the inclusion of a personalised action plan built into the app. Such action plans exist for other chronic conditions, such as asthma, and can help both patients and those around them to recognise issues that can be managed at home, including a step wise list of actions, and which should prompt (re-)engagement with health services [288].

Peer support features were highlighted as an important component to be built into the app, and represents a valuable asset to a self-management strategy in which patient education can stem from the lived experiences of peers [289]. Although there is little research on the effects of peer support interventions for people with acquired brain injury [290], co-developers highlighted it as a core component of their journey. This is not surprising, however, as co-developers were recruited through a local Headway peer support group. Engagement with peer support is generally low though peer support groups have been shown to increase patient empowerment, coping abilities and quality of life [291]. As such, increasing the opportunity for people with brain injury to engage with peer support, and facilitate peer-to-peer connections would be valuable. One of the co-developers mentioned that, especially in the early stages, online communication with peers would have been more acceptable to them as they found leaving their home difficult. Therefore, the app should not only provide information about local face-to-face peer support groups, but should constitute an opportunity for patients to connect with peers online [292,293].

The app, as envisioned by the team of co-developers constitutes a strong basis for self-management, as its different components address the cornerstones of self-management strategies (Figure 7.8).

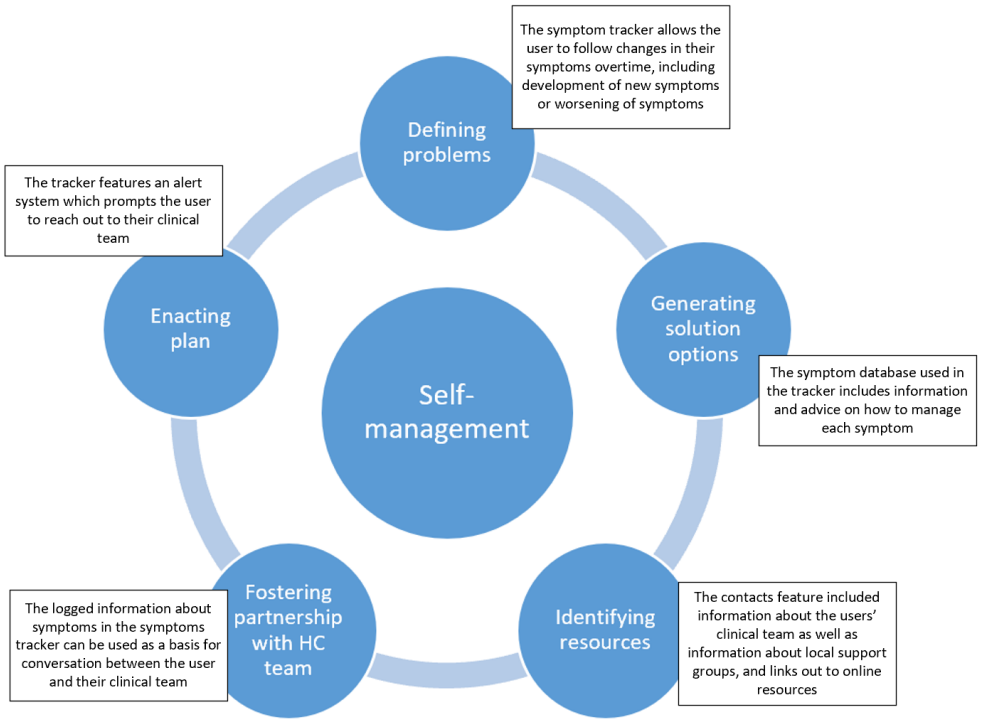


Figure 7.8. Mapping app features against self-management model

STRENGTHS AND LIMITATIONS

Digital healthcare

The lack of care pathways and difficulties in accessing face-to-face clinical care for people with P-TBI-S highlighted in previous chapters raises questions about potential benefits of developing digital healthcare options for this patient population. However, the development of a digital healthcare offer to fill gaps of traditional face-to-face care may increase health inequalities, which are already significant [294]. As such, they should not be conceived as a replacement, but rather as a complement to standard care [295]. On the other hand, it may be argued that "something is better than nothing" and that a successful digital-based self-management platform for brain injury survivor may further highlight the need for this type of service to be developed offline, and thus reach people who are not able or willing to engage with digital healthcare.

The importance of having strong digital healthcare alongside standard face-to-face care may have been most strongly highlighted during the COVID-19 pandemic. In the UK, many community-based services, and non-urgent care have either been suspended or cancelled. A strong digital healthcare provision for patients who can receive sufficient care and support without face-to-face contact could limit the negative effects of delayed care and ensure that patients do not fall through the gaps of the system, whether systemic or new and developing due to unforeseen changes in the public health context [296].

Proposed app design

The app imagined by the development group shares features with a number of existing productivity, social, and healthcare apps. In particular, the desire for accessible summary of medical appointment is reminiscent of the current effort deployed by NHS Digital to empower patients by giving them some level of access to their medical records through apps like Patient Access. The social elements described are akin to features proposed by Facebook, and multiple online dating apps, in the sense that they match profiles based on given data for "compatibility". In this case, such data would include location and type of brain injury in the first instance. Further work is needed to establish the sets of variables that would be required in proposing "matches" for app users. The calendar feature exists in many digital organisers. Google calendar was used as an example multiple times during the discussion, in the context of there being a need for third-party synchronisation of data in particular. Regardless, the imagined nature of this app as 'all-in-one' is potentially hard to juxtapose with the concern from the group for the app to be simple and easy to use.

The co-developers uncertainty and resistance regarding the use of data from the app for research purposes.

Mobile health apps have an interesting potential in the generation of real-world evidence [297]. The TBI population is notoriously hard to reach, and this has been pointed to as a key limiting factor is evaluating the medium to long-term effects of injury [3,6]. The design and uptaking of an app targeted at the wider TBI population holds the potential for the engagement of large numbers of patients, and a platform for the advertisement and recruitment of users into research studies. The Apple Heart Study [298] (a joint project between Stanford university and Apple Inc.) is a prime example of how digital technologies can contribute to research, even simply by enabling the recruitment of extremely large participant cohorts compared to traditional research recruitment approaches: in an 8 months recruitment window, ~420,000 people enrolled in the study (though only a small fraction were included in the end atrial fibrillation study). This new approach to research should be caveated, however, with the existence of commercial conflict of interest (the Apple Heart Study was funded by Apple Inc.), and ethical issues with the use of health data generated by users and seconded for use in research. This is an important point to consider with the design of the app presented in this chapter, as it raises a major question about funding. Indeed, this app would incur development, distribution, and maintenance costs. These costs can be addressed via three routes: commercial, public, or research funds. In all cases, app users would contribute either financially or through the data they produce, the latter being a likely option in a service development context.

PPI process

In 2018, Brighton et al. [299] tested the feasibility of using online platform for PPI. They found that the use of an online forum was functional, feasible and acceptable to patients and highlighted 4 key questions to consider in the design of an online PPI platform. These questions and how this PPI work relates to them are presented in Table 7.3.

Table 7.3. Key considerations for online PPI

How does it work?	Standard message-based structure, platform that co-developers were already familiar with, limited functionalities (single chat thread) for ease of use and easy access to all information.
How does it engage people?	Short text-length messages, with periodic prompts from the researcher. Lack of 'admin' tag next to researcher's messages facilitated the view as level playing field for all participants. Opportunities for co-developers to share link with peers who may be interested in participating (although this did not occur in this work)
How does it empower people?	Co-developers free to engage at times most suitable to them, allowing them to come back to earlier discussion points easily using the function allowing for replies to specific messages.
What is the impact?	Flexibility in participation afforded by the asynchronous message-based chat model. Allowed the researcher to easily access information upon creating the app designs. The use of a messaging app was also convenient for the presentation of the app designs, which co-developers received directly to their devices

This project aimed to include expert patients from the initial development stages, to ensure that the outcomes stayed relevant. However, the group of brain injury survivors who took part in this work had suffered injuries on the more severe end of the spectrum. The key issue for people with difficulties after milder brain injury is that they often struggle to find their way to support services, therefore it is unsurprising that this population could not be captured through Headway. Regardless, it is likely that some of the app features proposed would be helpful for people who have had a milder TBI, specifically in that, through its

symptom tracking and alert system, the app may assist people with unmet meets to connect or reconnect with appropriate services.

The use of a phone-based messaging platform for this PPI work carries the caveat that the views of people who are not already users with phone apps were not represented. In addition, it is fair to assume that the recruitment of co-developers from a peer support group limits the inclusion of brain injury survivors who are completely disconnected from this type of support structure. As such, the views of the co-developers are certainly not a representation of these of all brain injury survivors. In the context of this work, which was the early stages of the development process, this pragmatic approach to PPI seems appropriate. In later stages however, it will be crucial to engage with a broader spectrum of the brain injury survivor population.

Beyond concerns of representativity of the co-developers, one of the challenges with using an online messaging platform for this work was that it was difficult to ensure that everyone was engaged as conversations stretched across hours and days. The lack of funding for this study made face-to-face meetings difficult, as there were no funds to compensate co-developers for their work. While the initial presentation and registration of interest took place during one of the Headway sessions, it did not feel appropriate to carry out further work in this setting as it would have taken valuable peer support time away from the co-developers. This lack of opportunity for compensation created some unease in determining how much input would be appropriate to expect from the group, and possibly reinforced perceived power imbalances between the researcher and the brain injury survivors.

IMPLICATIONS FOR PRACTICE AND FUTURE RESEARCH

Despite these shortcomings, the need for better support for people with brain injury is evident. Systematic follow-up of patients following brain injury of any severity has been shown to be inefficient, and is therefore not currently recommended in clinical practice guidelines. As such, it is inevitable that some patients who would benefit from further care are facing substantial delays in doing so, or even not accessing services at all. It appears therefore that there is a need for ‘something’ to bridge this gap and identify patients who need access to services.

The cognitive difficulties inherently associated with brain injury can render the simultaneous use of several apps difficult, therefore there may be some value in creating a centralised platform proposing different features targeted more specifically to self-management after brain injury.

Used on a large enough sample, data collected from such an app could give insight into outcomes of brain injuries of various degrees, including further exploration of delayed-

onset P-TBI-S. This data could also be used to examine care journeys in the community, information which is currently severely lacking from the brain injury literature. Finally, the user-base of such an app could constitute a database of potential research participants. More work is needed to explore issues pertaining to privacy, data security, informed consent and data sharing, which emerged from discussion around the use of data from the app for research purposes.

CONCLUSIONS

This chapter set out to initiate the development of a self-management platform for people with P-TBI-S, and to examine to propensity of such a platform to be used for research purposes. This work was carried out in collaboration with brain injury survivors and guided by 2 research questions:

1. What feature would be useful to people with P-TBI-S in a mobile app for self-management?
2. Would the use of a mobile app for research purposes be acceptable to people with P-TBI-S?

The app features highlighted by brain injury survivors as important to promote self-management include sources of reliable and dynamically presented information regarding each individual's specific set of symptoms. This feature should be paired with alerts based on input into a symptom tracker that should prompt users to seeks help from medical or other support providers as appropriate. Another feature proposed was a calendar, to help users keep track of multiple appointments with various healthcare providers. This concern aligned with findings from the review of the literature (Part I) and the study presented in Chapter 6, which showed that management of P-TBI-S may involve a wide range of healthcare and support professionals, and that those are not necessarily well coordinated. Finally, a social media platform enabling contact between different app users was desirable.

There was no group consensus regarding the use of the app to mediate recruitment of app users into research studies and/or exploitation of app data for research into care pathways. It seems that co-developers found it difficult to imagine what that would look like in practice and were keen to see a working app prototype in order to better understand the data it could collect and whether and how that data could be used in research contexts.

Nonetheless the development of this mobile app for self-management and research purposes offers a promising complement to both the healthcare support of people with P-TBI-S, which may be lacking or inconsistent, and to the support of future research endeavours aiming at working with a wider, more representative group of the P-TBI-S population.

CHAPTER 8 – DISCUSSION AND NEXT STEPS

KEY FINDINGS

The findings from the work presented in this thesis confirm vast amounts of anecdotal evidence regarding the lack of guidance for the care of people with P-TBI-S, the fragmented existing care pathways, the variability of care journeys and the difficulties in capturing this patient group in both research and clinical contexts.

With an overarching aim of defining robust care pathways for people with Post TBI Syndrome (P-TBI-S), this work set out to explore the structure of the care system and the processes of care for people with P-TBI-S with three main objectives:

1. Understand the state of rehabilitation care for people with P-TBI-S
2. Identify core elements of a care pathway for people with P-TBI-S
3. Propose new avenues to explore care journeys in large and varied samples

UNDERSTAND THE STATE OF REHABILITATION CARE FOR PEOPLE WITH P-TBI-S

Rehabilitation for people with P-TBI-S is not guided by defined care pathways. The scoping review (Chapter 3) showed that knowledge of pathways for this patient population is limited. In particular, research investigating broad care pathways, from acute to community services, in the literature is insufficient. While calls for research in this area are numerous, few studies explore rehabilitation for this patient population. Instead, many studies are narrow in scope, evaluating a single service or strictly limited subgroups of the Traumatic Brain Injury (TBI) population such as athlete and military populations. A result of the fragmented research literature is a lack of high-level, statistically significant and generalizable evidence that should form the basis for clinical guidelines. In addition, the heterogeneity in patient and injury characteristics render the production of 'one-size-fits-all' recommendations difficult. As a consequence, guidelines for the rehabilitation of the wider population of people with P-TBI-S are scarce, remain vague in their recommendations, and access to further care is subject to availability and accessibility of services in local areas. This finding was corroborated by the results of the study presented in Chapter 6, which painted a picture of highly variable care journeys in a complex care system where care for people with P-TBI-S is largely determined by availability of services in each Trust's and Clinical Commissioning Group's catchment area. The issue of accessibility of services also emerged clearly from this study which highlighted an important fragmentation of care routes, especially in the transition from acute to community settings. The existence of poorly connected silos of care is likely to significantly contribute to the propensity for patients with P-TBI-S to fall through the gaps. Access to care upon emergence

of P-TBI-S largely relies on patients to recognize their need for support and be knowledgeable about the services they need to reach out to.

Both the review of the literature (Part I) and the study presented in Chapter 6 highlight a central role for early patient education about TBI and its consequences. The analysis of Patient Information Leaflets (PILs) presented in Chapter 5 showed that educational materials distributed to patients with head injury at discharge from A&E (Chapter 5) was often vague and did not account for the myriad of symptom combinations that can emerge in people with P-TBI-S. Overall, the risk of developing persisting symptoms appeared underplayed in the PILs. The course of action for patients with persisting symptoms was similar across the different major trauma networks, in that they should reach out to their GP. This finding was in line with results from the pathways mapping study (Chapter 6), which showed that access to rehabilitation for people with P-TBI-S in the community was largely mediated by their GP. That study highlighted additional routes into rehabilitation care for patients who has been admitted into hospital following their initial injury, including direct referral into rehabilitation services from the acute setting, or referral mediated by rehabilitation consultants seen on an outpatient basis following discharge from acute care.

It is likely that an important proportion of people with mTBI do not seek help from acute care services and may instead present to their GP some time after injury. The role of GPs in providing TBI education and managing P-TBI-S was found to be central. Despite this, it is unclear whether all GPs are sufficiently knowledgeable about the subtleties and challenges of P-TBI-S, and about the available services to be in a position to offer appropriate support. Moreover, the variability of service provision across different areas limit their options in referring patients onwards to specialist services.

IDENTIFY CORE ELEMENTS OF A CARE PATHWAY FOR PEOPLE WITH P-TBI-S

This work highlighted difficulties in defining large care pathways encompassing acute and community-based settings. These notably included the variability in service availability and in patients' care journeys. The review of the literature (Chapter 3), and within it the scarcity of specific recommendations for the rehabilitation of people with P-TBI-S, suggested a strong reliance on local service provision to ensure continuity of care for this patient group. It is likely that the lack of clinical practice guidelines hinders the development and accessibility of such services for people with P-TBI-S, and thus contributes to the variability of care journeys. The analysis of case reports (Chapter 4) showed that these patients may use a considerable amount of resource in community care settings, largely because they inefficiently navigate the care system before accessing the appropriate service. The examination of case reports however showed a number of similarities in both the care routes and the care needs of these patients. This suggests there may be room for

rehabilitation recommendations applicable to the wider population of patients who experience P-TBI-S.

Points of convergence in care routes were also apparent in the interview study (Chapter 6), thus highlighting key elements that should be part of the care offer for people with P-TBI-S. In particular, better and more specific patient education materials should be available. These should be easily accessible to all patients with P-TBI-S, whether or not and regardless of when and where they seek help. While not all patients with mTBI require specific rehabilitation input, a large proportion of these patients will experience P-TBI-S. As such, specialist multidisciplinary services (including psychology, neuropsychology, occupational therapy and vocational therapy) should be available to them, and should be accessible through clinician referral at all levels of care (i.e. acute or community settings) as well as through self-referral. Such self-referral options are already available for other services, such as sexual health clinics or mental health support services and it is therefore likely that this may be feasible for this patient population.

PROPOSE NEW AVENUES TO EXPLORE CARE JOURNEYS IN LARGE AND VARIED SAMPLES

The review of the literature (Chapter 3) suggested a lack of clear and specific clinical practice guidelines for the rehabilitation of people with P-TBI-S, partly due to methodological challenges in the field. There is a lack of appropriate services specifically designed for people with P-TBI-S following head injuries on the milder end of the spectrum, and who do not show need for multidisciplinary input at acute assessment. The difficulty in re-accessing rehabilitation services once in the community suggests that the border between acute and community services is relatively impermeable (Chapter 6). This structure of care services fails to account for the often delayed emergence and fluctuating nature of P-TBI-S. The paucity of patient education (Chapter 5) about P-TBI-S coupled with potential cognitive difficulties associated with it, and the limited availability and accessibility of appropriate services likely contributes to the number of people with P-TBI-S with unmet needs in the community. The lack of relevant research and care guidelines for this patient population presents a significant challenge to the development of appropriate services. Meanwhile, an important proportion of patients with P-TBI-S are left uncared for in the community, and may struggle to re-adjust following an 'invisible' injury. These findings highlighted gaps in both research and P-TBI-S management.

In terms of research, the understanding of care pathways for people with P-TBI-S is limited, particularly in community care settings, where access to care is largely unchecked by clinical guidelines, and thus complex and variable. The lack of care pathways and resulting variable care journeys render the recruitment of large cohorts of patients within a single setting

difficult. Prospective cohort studies tend to recruit patients early on in their journey, in acute settings such as A&E departments. In the context of exploring P-TBI-S, this approach would necessitate extended follow up, increasing chances of high attrition and study costs [103]. Alternative recruitment sites at later stages of care, through TBI clinics for example may facilitate the identification of people with P-TBI-S, but exclude those who have fallen through the gaps of care. This may be appropriate to explore outcomes of P-TBI-S, but the de facto exclusion of people who do not attend clinic is problematic for studies aiming to explore care journeys.

There is a need for more data both locally and nationally to obtain a richer and more comprehensive picture of care pathways and pathway variation. The mapping of pathways locally through interviews of clinical and non-clinical support stakeholders was successful in highlighting key decision-making points and factors influencing decisions leading to pathway variation. This study highlighted local service availability and accessibility as a critical factor for pathway variation, suggesting that the map produced in this study is very much anchored in the local area, and may not be applicable to other parts of the country. The methods used, however, showed that this process can be conducted relatively quickly and is likely to be useful in contrasting actual patient journeys to clinicians' understanding of the system. The recruitment challenges faced in the study of patients' care journeys through interviews suggest a need for novel approaches to the identification of people with P-TBI-S.

This difficulty in identifying patients eligible for research may in part emerge from reasons similar to those explaining low engagement of people with P-TBI-S with relevant services: that is people who are most in need of support are those who have fallen through the gaps of the care system. In addition to improving recruitment of this population into research projects, there is a pressing need to ensure that people who experience P-TBI-S can find their way to care services as needed.

The need for novel research approaches and enhanced support for people with P-TBI-S was explored Chapter 7. The identification of points of convergence of patients with variable profiles towards specific care services (Chapter 4, Chapter 6) suggest that A&E department, brain injury clinics and GP surgeries may be suitable points of recruitment, but not sufficient to capture the wider population of people with P-TBI-S. The work presented in Chapter 7 aims at circumventing the recruitment of participants through pre-determined healthcare services, and open future research to the inclusion of people with P-TBI-S who may not be receiving care and support through typical healthcare structures. This collaborative work with brain injury survivors culminated in the initial design of a mobile app. This app should combine elements to support self-management through an education package and

symptom monitoring features, as well as creating opportunities for research on P-TBI-S and service use for this patient population.

The work in this thesis proposed alternative ways to explore care pathways and care journeys, through the mapping of all potential care routes through interviews with health and support stakeholders in a given area, and through the development of a mobile app with the potential to passively monitor access to care services for a large cohort of people with TBI.

STRENGTHS AND LIMITATIONS

STRENGTHS

The work presented in this thesis combines traditional healthcare research methods and novel techniques to explore the rehabilitation of people with P-TBI-S. The combination of multiple methods to address the objectives of this study allowed for some level of triangulation of findings. Indeed, the results from the various studies invariably pointed to three main conclusions:

1. There is a lack of defined pathways
2. This lack of pathways leads to silos of care, which makes for a complex care system that is difficult for both patients and healthcare professionals to navigate
3. There are common elements in both the care need and care routes of people with P-TBI-S, which suggest that some level of coordinated rehabilitation input is warranted.

The review of case reports was innovative, as no evidence of similar work was identified. The amount of information pertaining to care needs and care routes extracted from these case reports highlighted the potential for studies using this type of design to be better integrated into evidence-based medicine. The scoping review did not lead to the generation of an obvious research question for a traditional systematic review, as is typical with this type of work. However, it may be that the best next step, in light of the success of the case reports analysis, is to conduct a systematic review of all case reports about TBI patients.

The Role-Activity Diagram modelling approach to the mapping of care routes with healthcare and support professionals was also innovative and surprising in the amount of detail it generated in spite of the relatively low number of interviewees. This approach has the potential to be exported to different healthcare systems, both nationally and internationally, and is applicable to work on conditions other than TBI. This method allowed for a deep and nuanced understanding of the care provision for people with P-TBI-S, including substantial information pertaining to decision-making processes. In addition, this

work has set the basis for complementary quantitative work, in which pathway variation analysis may be conducted following collection of patient service use data at different points along the identified routes.

LIMITATIONS

This work presented three key limitations (limitations of individual studies are presented in their respective chapters): the first was the lack of patient perspectives, the second was the lack of service use data, and the third was the lack of exploration of outcomes of care.

Lack of patient perspectives

The project plan included an interview study with people with P-TBI-S in order to gain patient perspectives on P-TBI-S care in the local area (Chapter 2). This would have allowed for the production of a pathway map to be compared to this produced through the interviews of healthcare and support professionals. A study was launched in September 2019 to recruit patients through a brain injury clinic for interview. The recruitment process was strictly guided by recommendations from the ethics committee, by which the patient was informed of the study by their clinician through an information sheet, and then needed to contact the researcher if they were interested in participating. The study was suspended in late December 2019 because of the constraints of the limited timeframe of this PhD project. In that time, only one patient expressed interest in participating and was interviewed.

This failure to recruit participants for this study raises a number of interesting points regarding engagement in research for this patient group, and the recruitment of research participants in clinical settings more widely [300].

The first is that the recruitment process itself may have limited recruitment numbers: Health Research Authority restrictions on the ability of researchers to approach and recruit potential participants in healthcare settings, and on sharing of patient data (including contact information) from healthcare professionals to researcher without explicit patient consent leave few options for recruitment. These restrictions increase pressures on clinicians to mediate recruitment into research studies themselves, in addition to their caring responsibilities. This process also puts researchers without clinical backgrounds or responsibilities at a disadvantage. These researchers therefore need to rely on strong professional connections with clinicians, which may be especially challenging for early career researchers, for whom these networks are likely to be smaller and less cemented than those of their more senior counterparts.

> "If you are identifying patients as potential study participants that you already treat or care for, there is no issue, as these people will know who you are and will not be surprised to be approached by you. However, if you want to identify and contact other patients with a particular condition, you will need a legal basis for accessing their medical notes. Alternatively, somebody that does have an appropriate legal basis (such as a member of their care team) can do this on your behalf."
>
> HRA website [301]

The second is that it is highly likely and reasonable that advertising research was not the rehabilitation consultant's priority upon seeing their patient, in a context where the role of senior clinicians already encompasses responsibilities beyond patient care alone, such as significant administrative tasks. The limited consultation time was also a likely barrier to the advertisement of the research project.

The third may be that attempting to recruit participants from a Brain Injury clinic was unlikely to lead to the identification of high numbers of eligible patients. As identified in Chapter 6, clinic attendance following TBI is low, and those attending are likely to have sustained injuries on the more severe end of the brain injury spectrum (Chapter 1). As such, a large proportion of patients presenting at clinic for follow-up is likely to have comprised of individuals not eligible for participation in this study. An alternative recruitment site would be GP surgeries, although recruitment would likely have been slower still, as people presenting to their GP with P-TBI-S are unlikely to form the bulk of patients seen in primary care, and GPs may not be aware of any mild TBI history in their patient, or link presenting complaints with a past head injury (Chapter 6). Moreover, GP consultations face notoriously short time constraints, thus decreasing opportunities for research advertisement.

The fourth is that the onus to contact the researcher for participation was on the patient, adding yet another barrier to recruitment, in addition to the patient's decision to attend the TBI clinic for P-TBI-S concerns, the consultant taking the time to advertise the study, the patient taking the information sheet home, and deciding whether they are interested in participating.

Finally, there was no financial incentive for participation in the study, which may have discouraged patients from participating.

Lack of service use data

The second main limitation of this project was the lack of collection of service use data. This type of work was not included within the remit of this thesis because of the lack of

knowledge about care journeys and thus lack of insight into which services may be used by this patient population (Chapter 2). However, although the use of patient records to map care journeys may have been difficult, the collection of service use data at specific points of care might have contributed to a better understanding of service needs for this population. Indeed, one of the challenges in the development of rehabilitation services for people with P-TBI-S is the lack of understanding of the scale of the problem, that is, the size of the population who may need access to rehabilitation services (Chapter 1). Examining consecutive A&E attendances for mild TBI and subsequent decisions to discharge or admit patients would have shed light on the numbers of patients with mTBI in the local area. One of the findings that emerged from clinician interviews (Chapter 6) is the high rate of non-attendance to follow-up brain injury clinic: formally evaluating this would also highlight the proportion of patients with potential P-TBI-S in the community. It could have also been interesting to collect attendance information to evaluate the time between referral and attendance to brain injury clinics to evaluate the risk of unchecked P-TBI-S due to delays in access to care. Finally, an evaluation of attendance to GP surgeries following TBI would have highlighted whether this route of access for further TBI care is widely used, as results from the work presented in this thesis suggest it may be.

Lack of care outcome data

Lastly, no outcome data was collected as part of this thesis. Although this did not fall within the scope of this work (Chapter 2), an evaluation of outcomes of care for people attending the brain injury clinic or their GP with P-TBI-S complaints would be valuable in determining a range of care needs and whether those needs are satisfactorily addressed within existing care structures. However, this work would be incomplete as not all people with P-TBI-S attend clinic or seek support from their GP. A larger exploration of care outcomes will be included in later stages of research and is discussed later on in this chapter.

REFLECTIVE SUMMARY

The research presented in this thesis are based on my understanding of issues in the design and delivery of healthcare and support services for people with P-TBI-S, my interpretation of the results, and my personal characteristics as a researcher [302]. Here I present a reflection on my positionality in approaching the HCP interviews presented in Chapter 6 and the PPI work presented in Chapter 7.

While conducting the HCP interviews, I was concerned about the effects of my existing understanding of healthcare and support for people with P-TBI-S. My experience working on a major trauma ward led me to feeling like oftentimes, mild TBIs are overshadowed by other injuries, and that as a result, some patients may not receive the appropriate support

for their TBI. In addition, as I had conducted the scoping review of the literature on care pathways and care journeys for people with P-TBI-S, I knew that little formal protocols were likely to be in place for this patient population. As such, I was conscious that I should not be too forward with my own understanding of the situation, so that participants felt free to expose their own views. I felt that the semi-structured nature of the interviews allowed participants to be open about their experiences and understanding of care for people with P-TBI-S, as I ensured that the first prompt was for participants to explain how a patient with mTBI/P-TBI-S would be care for in the setting relevant each interviewee role.

I was also concerned that my lack of background as a HCP or as a NHS worker would be perceived as a lack of legitimacy in researching care pathways. My concern was that HCPs would over-simplify some of the issues, both in terms of clinical notions and governance and administrative structure for fear that I would not be familiar enough with these aspects of the work to understand their relevance. I was conscious of finding the right balance between exposing my own understanding without leading the conversation towards statement that would only comfort but not challenge my views. In reality, I found that my lack of professional clinical or NHS background was useful as the interviewees broke down concepts that they may have otherwise glossed over.

For example, in this conversation with a clinical psychologist, my lack of experience led to the interviewee detailing clinical assessment steps.

> IK: […] So do you have any specific assessment tools that you use for cognitive assessments?
>
> ID002: Mm-hmm
>
> IK: So, which are they?
>
> ID002: We have a standard battery, which for me I would - do you wanna know all the names and everything?
>
> IK: Yes
>
> ID002: OKay. We all screen for mood so we use the Hospital Anxiety and Depression scale, to screen for mood. If there's concerns about suicidal ideation, then I would do something extra such as the Beck Depression Inventory. So that's the mood stuff, we also ask about psychiatric symptoms, and kind of suicidal ideaiton. Then form a cognitive point of view we do screening for pre-morbid ability, we use the Test Of Premorbid Function, then we would do, or I'd some some general sort of cognitive screen. Some people argue it's a screen, some people argue it's a bit more in depth cognitive assessment, but I use the Repeatable Battery for the Assessment of Neuropsychological Status, so it gives us a kind of overview of someone's abilities. We do executive tests, so I typically do the Hayling from the Hayling and Brixton test, I do subtests from the Behavioural Assessment of Dysexcutive Syndrome. So I'd routinely a key search, an action programme, a zoom app, I can't think of anything else. We quite

> often will do a trails test from something called the D-KEFS, or the Delis Kaplan something [Delis Kaplan Executive Function System], and we usually factor in a test of effort, as a way to measure someone's level of engagement in the assessment process, and because sometimes people will have other influences that will affect performace, which will be anything from compensation to low mood, to fear of not being believed, so we like to just get a baseline in terms of their effort and engagement. So we use a Test Of Memory Malingering and/or the Green's word memory test.

I was also concerned about my positionality for the development of the mobile platform for brain injury survivors. Having not personally sustained a brain injury, I was concerned about the effect that my lack of direct experience with brain injury may have on my understanding of what would constitute helpful and acceptable support for survivors. This was one of the main drivers for the anchoring of this work within a PPI approach working with brain injury survivors as co-developers. One of the challenges with this approach lied with my role as the researcher, as I feared that this might position me as the "expert" whilst being somewhat removed from the day-to-day difficulties associated with brain injury. I found that the co-developers understood that their lived experiences were valued, and critical for the development of this platform, as they shared their feelings about previous experience with research engagement.

> "After the initial illness it's hard to know how to move on and there's not much transition. […] We all have experiences that can help other people"
>
> "I take part in lots of medical research and sometimes I feel I'm not my own person anymore. I feel my body becomes everyone else's research and sometimes I want to claim my body back if that makes sense"

CONSIDERATIONS FOR FURTHER WORK

Besides the technical limitations of the project discussed above, the findings of this thesis are limited by two core elements: firstly, the reasons for emergence of P-TBI-S were not explored; secondly, this work lacked perspectives from some key stakeholders of the healthcare system.

BIOPSYCHOSOCIAL VIEW OF P-TBI-S

Mild TBI has been described as "the most complicated disease of the most complex organ of the body" [303, p.1208]. In spite of the increased awareness about TBI and its consequences

worldwide, the reasons why patients can experience disproportionately severe symptoms following milder TBIs are still opaque. It is possible that P-TBI-S stems from pathological processes including subtle structural damage and inflammatory responses in the brain (Chapter 1). It is unlikely however that these changes alone can explain the complexity and variability of P-TBI-S. P-TBI-S is likely to be multifactorial, and should be viewed through a biopsychosocial lens.

In the 1970s and 1980s, the standard biomedical models of health –or ill-health— started transforming into more inclusive biopsychosocial models [304]. In the 1980s, McKeown posited, in his Social Theory, that "medical science and services are misdirected, and society's investment in health is not well used, because they rest on an erroneous assumption about the basis of health. [... This] approach has led to indifference to the external influences and personal behaviour which are the predominant determinants" [305, p.xv-xvi]. In his commentary, Le Fanu [306] argues that the Social Theory was well received by politicians and policy-makers because they represent a strong (financial) and convenient argument that attention (money) should be directed at, instead of (expensive) medical services, (cheaper) prevention and health promotion initiatives.

As a consequence, public health initiatives for the prevention of ill-health soared in the 1980s, and culminated in 1999 into a list of health tips published in 'Saving Lives: Our Healthier Nation' by England's Chief Medical Officer, Liam Donaldson [307, p.11]. Marmot [84] argues that this list, although consisting of well-meaning sound evidence-based advice is unlikely to make a difference to those who have the most to gain. This list indeed assumes that people's behaviour, or lack of health-positive behaviour, is a result of ignorance. This short-sight was evocatively highlighted by the alternative list published by the University of Bristol's Townsend Centre for International Poverty Research (Table 8.1).

Table 8.1. Health tips

Donaldson's health tips	Alternative tips
1) Don't smoke. If you can, stop. If you can't, cut down.	1) Don't be poor. If you can, stop. If you can't, try not to be poor for long.
2) Follow a balanced diet with plenty of fruit and vegetables.	2) Don't live in a deprived area. If you do, move.
3) Keep physically active.	3) Don't be disabled or have a disabled child.
4) Manage stress by, for example, talking things through and making time to relax.	4) Don't work in a stressful, low-paid manual job.
5) If you drink alcohol, do so in moderation.	5) Don't live in damp, low-quality housing or be homeless.
6) Cover up in the sun, and protect children from sunburn.	6) Be able to afford to pay for social activities and annual holidays.
7) Practise safer sex.	7) Don't be a lone parent.
8) Take up cancer screening opportunities	8) Claim all benefits to which you are entitled.
9) Be safe on the roads: follow the Highway Code.	9) Be able to afford to own a car.
10) Learn the First Aid ABC – airways, breathing, circulation.	10) Use education to improve your socio-economic position.

This second list is also made up of sound, evidence-based advice, but it highlights, more compellingly than the first, the lack of control that an individual may have over their circumstances. The advice given to patients following mild TBI (Chapter 5) is comparable to general health advice such as Donaldson's, and therefore presents similar limitations, leaving patients in more precarious socio-economic situations at risk of experiencing a protracted recovery.

The more holistic approach prescribed by biopsychosocial models of health enables the appraisal of not only the causes of good or ill-health (in this case, the absence or presence of P-TBI-S), but also the causes of these causes (here, why some people are more susceptible to experiencing P-TBI-S than others). In 2010, the Marmot review presented an account of social determinants of health in England [308]. This report highlighted the importance of contextualising health using individuals' circumstances, which expanded to include the broader social, economic and political context. Marmot argues that there is a significant social gradient in health, by which higher deprivation is associated with worse health. This social gradient in TBI outcomes has seldom been studied, but recent works suggest that this theory may apply to this patient population [309]. Interviews with clinicians (Chapter 6) also suggest that the patients' socio-economic status may influence their recovery trajectory. The 2020 update of the Marmot report indicates that health inequities in the UK are increasing [294].

This thesis largely focused on the perspectives of academics and healthcare professionals. These are valuable because they convey expert knowledge of both TBI and healthcare, however, they lack in perspectives brought by lived experience of TBI and related healthcare use that patients and their relatives can convey. As such, future work should include the perspectives of patients, not only on formal care but also on contextual factors that may promote or hinder recovery.

BEYOND THE BIOPSYCHOSOCIAL MODEL

The optimization and development of healthcare services for people with P-TBI-S must also take into account a third group of stakeholders: those who represent bodies governing health and social care service provision. This tripartite view of healthcare is pivotal to understanding the power dynamics affecting change in the system [84,310-312].

Each stakeholder group guiding policy change –the patients, the care professionals, and the actors of governing bodies– has different economic and political interests that may supersede simple concerns in improving the healthcare system [311]. Power imbalances between these different groups, generally favouring governing bodies, limit the scope of what is considered feasible change to the system (Figure 8.1).

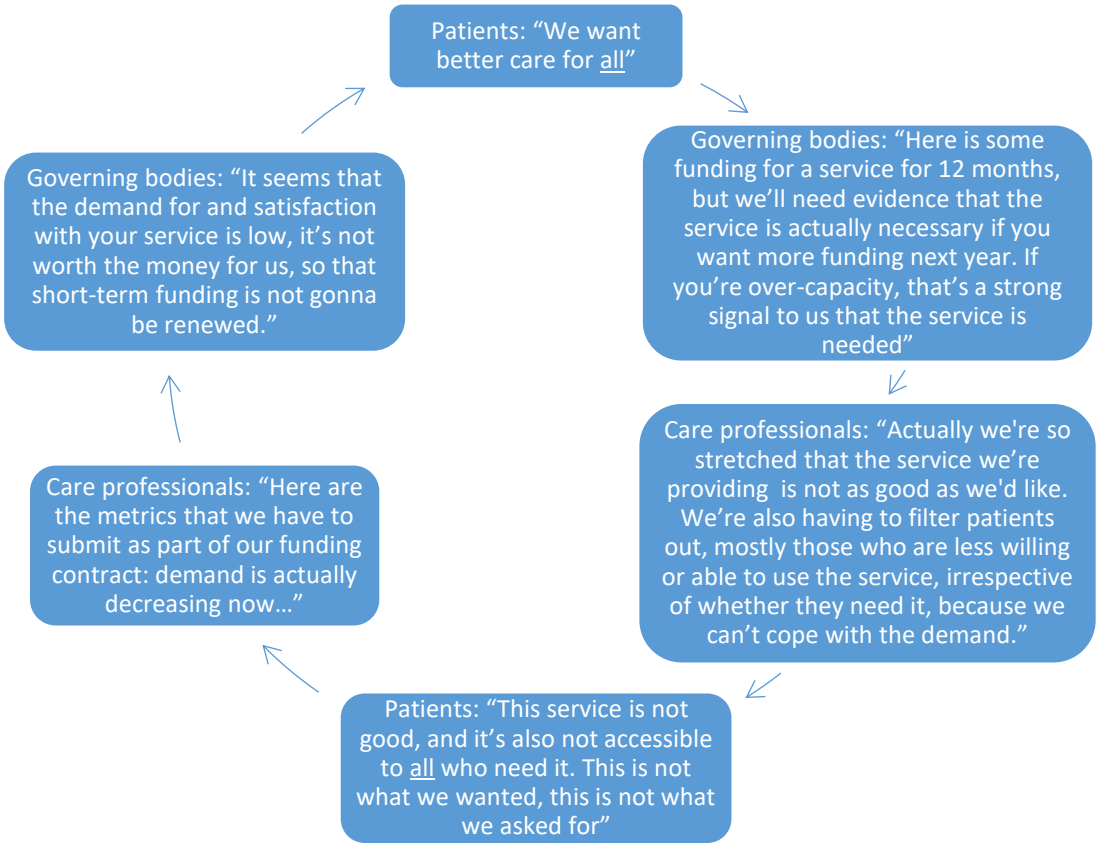


Figure 8.1. Power dynamics impeding change

It may be that broader issues in the UK healthcare system cannot be solved without true large-scale reform challenging these skewed power dynamics. However, better care for people with P-TBI-S is possible within the current constraints. A lack of national clinical guidelines should not stop local areas from evaluating need and developing appropriate services [313]. Thus, in addition to perspectives from patients and healthcare professionals, further research should involve collaboration with appropriate bodies governing health and care provision for people with P-TBI-S.

NEXT STEPS

In light of the findings of the work presented in this thesis, the challenges encountered, and the limitations highlighted previously, future work should include:

1. The use of any existing data to further the understanding of care journeys, particularly any existing service use data (which can be extracted from patient records at discrete points of care)
2. A more holistic exploration of patient perspectives and outcomes of care

3. A deeper understanding of care structures and governance of care services development to identify structural and political barriers to the development of services

The work carried out in collaboration with expert patients for the development of a self-management platform sets the foundation for the wider exploration of individual care journeys, within and beyond the boundaries of healthcare services, and the evaluation of care needs at different stages of recovery. It may also constitute a database of people with P-TBI-S who could be recruited for participation in further studies. This would fill one of the main gaps of the research in this field, that is, that it is difficult to recruit wide samples of patients because recruitment is typically carried out in pre-determined discrete services. The use of this app to identify service 'hotspots' in the patients' care journeys could contribute to dynamic identification of recruitment points, and allow for exploration of outcomes of care linked to specific services, thus addressing the last part of the Donabedian model presented in Chapter 2 (Figure 8.2). Access to information about care journeys could also allow for the exploration of the cumulative care outcomes of different care services, thus providing insight into the effectiveness of care journeys overall rather than this of isolated services.

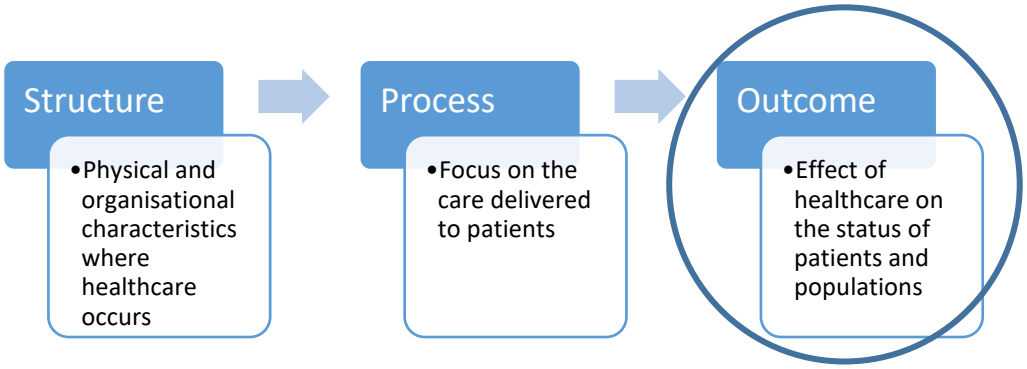


Figure 8.2. Donabedian model for quality of care

(adapted from NHS Improvement[97])

Additional work should evaluate processes of service development, including an exploration of the role and impact of policy and governing bodies such as Trusts and Clinical Commissioning Groups in addressing service needs in their catchment areas. This could be explored through case studies on the development of specific services, such as the brain injury clinic in Gloucester (highlighted in Chapter 6) with the aim to identify development steps, the nature of any barriers encountered in the development process, and the impact of this service on patient flow in other parts of the healthcare system and on patient outcomes.

CONCLUSION

The work presented in this thesis made a number of unique contributions to the literature. The scoping review presented in Chapter 3 is the first to survey a wide range of publications to understand the state of rehabilitation for people with P-TBI-S by focusing on wide care pathways. This area of research had previously been highlighted as an important gap in the literature, but the heterogeneity of samples typically chosen for TBI research had prevented the examination of care for the wider group of people with TBI. The use of a scoping review approach enabled the integration of a wide range of publications to clarify the current understanding of and approaches to care for a range of people with P-TBI-S. In addition, it highlighted the great potential for underused types of research such as case reports, to be compiled and used to identify points of convergence in the care needs and service use of an otherwise heterogeneous group of patients with P-TBI-S.

The review of the literature highlighted the lack of guidelines for the rehabilitation of people with P-TBI-S. However heterogeneous, people with P-TBI-S have common care needs, and convergence in the care and support services they access was also highlighted. However, the wide variety of stakeholders and services identified, in addition to complex and variable patterns of access to care (including substantial re-access loops between services) suggested inefficiencies in the system. Overall, the review of the literature suggested the existence of common elements that could be used to define care pathways, but the evidence was not sufficiently robust to advocate for strong care pathways for people with P-TBI-S. Without this type of evidence, it is unlikely that change to TBI care will be prescribed in a top-down approach, whereby national policy guides service development.

An alternative approach was therefore to explore the scope and feasibility of change at a more local level, following which the models of service optimisation and development may be exported to other areas. Evaluation of the rehabilitation provision at the local level confirmed the complexity of care journeys of people with P-TBI-S. The approach chosen for this work showed how care routes can be mapped in detail using novel qualitative methods, which allow for a deeper understanding of the factors influencing care for people with P-TBI-S. A care pathway should include well-designed supported self-management, clear routes for re-access to care services beyond the acute stage, and a specific rehabilitation offer that is independent of patient postcode, sufficiently resources, and easily accessible through open referrals from clinicians at all levels of care and through patient self-referral.

Though future work should explore the patient contextual factors that may impact P-TBI-S, it is also critical to better understand current healthcare use by this patient population. The difficulty brought by the lack of care guidelines is that patients' care journeys are highly variable, and thus any burden on inappropriate care services is likely to be diluted. In

addition, the work presented in this thesis suggested that people with P-TBI-S may not only fail to seek care, but also, when they do, fall through gaps between multiple care silos at numerous points along their care journey. In order to understand this variability in care journeys, there is a need to better identify the patient population in the early stages of P-TBI-S, comprehensively describe their usage of care services, explore their care needs, and propose ways to address those through increased supported self-management and/or through the development of services specific to this population. In either case, there is a need for clearly defined care pathways for people with P-TBI-S.

> *"At the end of every scientific paper there is a familiar coda: more research is needed, more research is needed. What, I wondered, if we added a new coda: more action is needed. It need not be discordant with the first"*
>
> *Marmot* [84, p.17]

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APPENDICES

Appendix 3.1. Search terms

	Care	Pathways	P-TBI-S	TBI	Limits
Search 1	Rehabilitation Pathways Care Pathways Integrated Care Patient Pathways		Post-Concussive Syndrome Post-Concussive Symptoms PCS	Traumatic Brain Injury TBI Concussion	-
Search 2	Rehabilitation Care Critical Patient Integrated Primary care Secondary care Tertiary care Treatment* Therap* Intervention* Follow-up Follow up Healthcare Health Care Medical Care Service* Decision-making Decision making Medical Clinical Community	Pathway* Plan* Continuity Delivery Referral* Management Organi?ation administration scheduling journey*	Post-Concussive syndrome Postconcussive syndrome Post-concussion syndrome Postconcussion syndrome Post-concussive symptom* Postconcussive symptom* Post-concussion symptom* Postconcussion symptom* PCS	Traumatic Brain Injur* TBI Mild traumatic Brain Injur* mTBI Head Injur* Mild Head injur* Brain injur* Concussion Brain Concussion	Paediatric Pediatric Children Animal*

Appendix 3.2. Search Booleans

Database	Search formula	N (pre-deduplication
PubMed	((traumatic brain injur* OR TBI OR Mild Traumatic Brain Injur* OR mTBI OR head injur* OR mild head injur* OR brain injur* OR concussion OR brain concussion) AND (post-concussive syndrome OR postconcussive syndrome OR post-concussion syndrome OR postconcussion syndrome OR post-concussive symptom* OR postconcussive symptom* OR post-concussion symptom* OR postconcussion symptom* OR PCS) AND (rehabilitation OR care OR critical OR patient OR integrated OR primary care OR secondary care OR tertiary care OR treatment* OR Therapy OR intervention* OR follow-up OR follow up OR healthcare OR health care OR medical care OR service* OR decision-making OR decision making OR medical OR clinical OR community) AND (pathway* OR plan OR planning OR continuity OR delivery OR referral* OR management OR organisation OR organization OR administration OR scheduling OR journey*) NOT (animal*) NOT (children OR paediatric OR pediatric))	530
Web of Science	TS=((traumatic brain injur* OR TBI OR Mild Traumatic Brain Injur* OR mTBI OR head injur* OR mild head injur* OR brain injur* OR concussion OR brain concussion) AND (post-concussive syndrome OR postconcussive syndrome OR post-concussion syndrome OR postconcussion syndrome OR post-concussive symptom* OR postconcussive symptom* OR post-concussion symptom* OR postconcussion symptom* OR PCS) AND (rehabilitation OR care OR critical OR patient OR integrated OR primary care OR secondary care OR tertiary care OR treatment* OR Therapy OR intervention* OR follow-up OR follow up OR healthcare OR health care OR medical care OR service* OR decision-making OR decision making OR medical OR clinical OR community) AND (pathway* OR plan OR planning OR continuity OR delivery OR referral* OR management OR organisation OR organization OR administration OR scheduling OR journey*) NOT (animal*) NOT (children OR paediatric OR pediatric))	484
CINAHL	TX (traumatic brain injur* OR TBI OR Mild Traumatic Brain Injur* OR mTBI OR head injur* OR mild head injur* OR brain injur* OR concussion OR brain concussion) AND TX (post-concussive syndrome OR postconcussive syndrome OR post-concussion syndrome OR postconcussion syndrome OR post-concussive symptom* OR postconcussive symptom* OR post-concussion symptom* OR postconcussion symptom* OR PCS) AND TX (rehabilitation OR care OR critical OR patient OR integrated OR primary care OR secondary care OR tertiary care OR treatment* OR Therapy OR intervention* OR follow-up OR follow up OR healthcare OR health care OR medical care OR service* OR decision-making OR decision making OR medical OR clinical OR community) AND TX (pathway* OR plan OR planning OR continuity OR delivery OR referral* OR management OR organisation OR organization OR administration OR scheduling OR journey*) NOT TX animal* NOT TX (children or paediatric or pediatric)	207
Embase	(((traumatic brain injur* or TBI or Mild Traumatic Brain Injur* or mTBI or head injur* or mild head injur* or brain injur* or concussion or brain concussion) and (post-concussive syndrome or postconcussive syndrome or post-concussion syndrome	618

	or postconcussion syndrome or post-concussive symptom* or postconcussive symptom* or post-concussion symptom* or postconcussion symptom* or PCS) and (rehabilitation or care or critical or patient or integrated or primary care or secondary care or tertiary care or treatment* or Therapy or intervention* or follow-up or follow up or healthcare or health care or medical care or service* or decision-making or decision making or medical or clinical or community) and (pathway* or plan or planning or continuity or delivery or referral* or management or organisation or organization or administration or scheduling or journey*)) not animal* not (children or pediatric or paediatric)).af.	
AMED	(((traumatic brain injur* or TBI or Mild Traumatic Brain Injur* or mTBI or head injur* or mild head injur* or brain injur* or concussion or brain concussion) and (post-concussive syndrome or postconcussive syndrome or post-concussion syndrome or postconcussion syndrome or post-concussive symptom* or postconcussive symptom* or post-concussion symptom* or postconcussion symptom* or PCS) and (rehabilitation or care or critical or patient or integrated or primary care or secondary care or tertiary care or treatment* or Therapy or intervention* or follow-up or follow up or healthcare or health care or medical care or service* or decision-making or decision making or medical or clinical or community) and (pathway* or plan or planning or continuity or delivery or referral* or management or organisation or organization or administration or scheduling or journey*)) not animal* not (children or pediatric or paediatric)).af.	21
Cochrane Library	((traumatic brain injur* OR TBI OR Mild Traumatic Brain Injur* OR mTBI OR head injur* OR mild head injur* OR brain injur* OR concussion OR brain concussion) AND (post-concussive syndrome OR postconcussive syndrome OR post-concussion syndrome OR postconcussion syndrome OR post-concussive symptom* OR postconcussive symptom* OR post-concussion symptom* OR postconcussion symptom* OR PCS) AND (rehabilitation OR care OR critical OR patient OR integrated OR primary care OR secondary care OR tertiary care OR treatment* OR Therapy OR intervention* OR follow-up OR follow up OR healthcare OR health care OR medical care OR service* OR decision-making OR decision making OR medical OR clinical OR community) AND (pathway* OR plan OR planning OR continuity OR delivery OR referral* OR management OR organisation OR organization OR administration OR scheduling OR journey*) NOT (animal*) NOT (children OR paediatric OR pediatric))	126

Appendix 4.1. ICF factors included in the R-CS, comprehensive TBI-CS and brief TBI-CS T

Key: 1 = included in core set, 0 = not included in core set

Code	Label	Rehab	Comp. TBI	Brief TBI
b110	consciousness functions	0	1	1
b114	orientation functions	0	1	0
b126	temperament and personality functions	0	1	0
b130	energy and drive functions	1	1	1
b134	sleep functions	1	1	0
b140	attention functions	0	1	1
b144	memory functions	0	1	1
b147	psychomotor functions	0	1	0
b152	emotional functions	1	1	1
b156	perceptual functions	0	1	0
b160	thought functions	0	1	0
b164	higher-level cognitive functions	0	1	1
b167	mental functions of language	0	1	0
b210	seeing functions	0	1	0
b215	functions of structures adjoining the eye	0	1	0
b235	vestibular functions	0	1	0
b240	sensations associated with hearing and vestibular functions	0	1	0
b255	smell function	0	1	0
b260	proprioceptive function	0	1	0
b280	sensation of pain	1	1	1
b310	voice function	0	1	0
b320	articulation function	0	1	0
b330	fluency and rhythm of speech functions	0	1	0
b420	blood pressure functions	0	1	0
b455	exercise tolerance functions	1	1	0
b510	ingestion functions	0	1	0
b525	defecation functions	0	1	0
b555	endocrine gland functions	0	1	0
b620	urination functions	1	1	0
b640	sexual functions	1	1	0
b710	mobility of joint functions	1	1	0
b730	muscle power functions	1	1	0
b735	muscle tone functions	0	1	0
b755	involuntary movement reaction functions	0	1	0
b760	control of voluntary movement functions	0	1	1
b765	involuntary movement functions	0	1	0
b770	gait pattern functions	0	1	0

d110	watching	0	1	0
d115	listening	0	1	0
d155	acquiring skills	0	1	0
d160	focusing attention	0	1	0
d163	thinking	0	1	0
d166	reading	0	1	0
d170	writing	0	1	0
d175	problem solving	0	1	0
d177	making decisions	0	1	0
d210	undertaking a single task	0	1	0
d220	undertaking multiple tasks	0	1	0
d230	carrying out daily routine	1	1	1
d240	handling stress and other psychological demands	1	1	0
d310	communicating with - receiving - spoken messages	0	1	0
d315	communicating with - receiving - nonverbal messages	0	1	0
d330	speaking	0	1	0
d335	producing nonverbal messages	0	1	0
d345	writing messages	0	1	0
d350	conversation	0	1	1
d360	using communication devices and techniques	0	1	0
d410	changing basic body position	1	1	0
d415	maintaining a body position	1	1	0
d420	transferring oneself	1	1	0
d430	lifting and carrying objects	0	1	0
d440	fine hand use	0	1	0
d445	hand and arm use	0	1	0
d450	walking	1	1	1
d455	moving around	1	1	0
d465	moving around using equipment	1	1	0
d470	using transportation	1	1	0
d475	driving	0	1	0
d510	washing oneself	1	1	0
d520	caring for body parts	1	1	0
d530	toileting	1	1	0
d540	dressing	1	1	0
d550	eating	1	1	0
d560	drinking	0	1	0
d570	looking after one’s health	1	1	0
d620	acquisition of goods and services	0	1	0
d630	preparing meals	0	1	0
d640	doing housework	1	1	0
d660	assisting others	1	1	0
d710	basic interpersonal interactions	1	1	0
d720	complex interpersonal interactions	0	1	1

d730	relating with strangers	0	1	0
d740	formal relationships	0	1	0
d750	informal social relationships	0	1	0
d760	family relationships	0	1	1
d770	intimate relationships	1	1	0
d825	vocational training	0	1	0
d830	higher education	0	1	0
d840	apprenticeship (work preparation)	0	1	0
d845	acquiring, keeping and terminating a job	0	1	1
d850	remunerative employment	1	1	0
d855	non-remunerative employment	0	1	0
d860	basic economic transactions	0	1	0
d865	complex economic transactions	0	1	0
d870	economic self-sufficiency	0	1	0
d910	community life	0	1	0
d920	recreation and leisure	1	1	1
d930	religion and spirituality	0	1	0
e1100	food	0	1	0
e1101	drugs	0	1	0
e1108	non-medicinal drugs and alcohol	0	1	0
e115	products and technology for personal use in daily living	0	1	1
e120	products and technology for personal indoor and outdoor mobility and transportation	0	1	1
e125	products and technology for communication	0	1	0
e135	products and technology for employment	0	1	0
e150	design, construction and building products and technology of buildings for public use	0	1	0
e155	design, construction and building products and technology of buildings for private use	0	1	0
e160	products and technology of land development	0	1	0
e165	assets	0	1	0
e210	physical geography	0	1	0
e250	sound	0	1	0
e310	immediate family	0	1	1
e315	extended family	0	1	0
e320	friends	0	1	1
e325	acquaintances, peers, colleagues, neighbours and community members	0	1	0
e330	people in positions of authority	0	1	0
e340	personal care providers and personal assistants	0	1	0
e355	health professionals	0	1	0
e360	other professionals	0	1	0
e410	individual attitudes of immediate family members	0	1	0
e415	individual attitudes of extended family members	0	1	0
e420	individual attitudes of friends	0	1	0

e425	individual attitudes of acquaintances, peers, colleagues, neighbours and community members	0	1	0
e440	individual attitudes of personal care providers and personal assistants	0	1	0
e450	individual attitudes of health professionals	0	1	0
e455	individual attitudes of other professionals	0	1	0
e460	societal attitudes	0	1	0
e515	architecture and construction services, systems, and policies	0	1	0
e525	housing services, systems and policies	0	1	0
e535	communication services, systems and policies	0	1	0
e540	transportation services, systems and policies	0	1	0
e550	legal services, systems and policies	0	1	0
e570	social security services, systems and policies	0	1	1
e575	general social support services, systems and policies	0	1	0
e580	health services, systems and policies	0	1	1
e585	education and training services, systems and policies	0	1	0
e590	labour and employment services, systems and policies	0	1	0
s110	structure of brain	0	1	1
s710	structure of head and neck region	0	1	0

Appendix 4.2. Full list of ICF factors identified in the case reports

Code	Label
s760	structure of trunk
s750	structure of lower extremity
s730	structure of upper extremity
s720	structure of shoulder region
s710	structure of head and neck region
s430	structure of respiratory system
s410	structure of cardiovascular system
s240	structure of external ear
s220	structure of eyeball
s110	structure of brain
e585	education and training services, systems and policies
e580	health services, systems and policies
e570	social security services, systems and policies
e565	economic services, systems and policies
e550	eating
e450	individual attitudes of health professionals
e430	individual attitudes of people in positions of authority
e425	individual attitudes of acquaintances, peers, colleagues, neighbours and community members
e410	individual attitudes of immediate family members
e355	health professionals
e330	people in positions of authority
e325	acquaintances, peers, colleagues, neighbours and community members
e320	friends
e310	immediate family
e110	products or substances for personal consumption
d920	recreation and leisure
d910	community life
d850	remunerative employment
d845	acquiring, keeping and terminating a job
d830	higher education
d799	structures related to movement, unspecified
d770	intimate relationships
d750	informal social relationships
d729	general interpersonal interactions, other specified and unspecified
d720	complex interpersonal interactions
d660	assisting others
d570	looking after one's health
d475	driving
d470	using transportation
d450	walking
d360	using communication devices and techniques

d240	handling stress and other psychological demands
d177	making decisions
d175	problem solving
d170	writing
d166	reading
b840	sensation related to the skin
b799	neuromusculoskeletal and movement-related functions, unspecified
b770	gait pattern functions
b765	involuntary movement functions
b760	control of voluntary movement functions
b755	involuntary movement reaction functions
b750	motor reflex functions
b730	muscle power functions
b535	sensations associated with the digestive system
b510	ingestion functions
b330	fluency and rhythm of speech functions
b299	sensory functions and pain, unspecified
b289	sensation of pain, other specified and unspecified
b280	sensation of pain
b265	touch function
b240	sensations associated with hearing and vestibular functions
b235	vestibular functions
b220	sensations associated with the eye and adjoining structures
b215	functions of structures adjoining the eye
b210	seeing functions
b199	mental functions, unspecified
b198	mental functions, other specified
b180	experience of self and time functions
b172	calculation functions
b167	mental functions of language
b164	higher-level cognitive functions
b160	thought functions
b152	emotional functions
b144	memory functions
b140	attention functions
b134	sleep functions
b130	energy and drive functions
b114	orientation functions
b110	consciousness functions

Appendix 4.3. Percentage of factors present in the TBI-CS by setting and domain

		Scene	Acute	Inpatient	Home/Work	Outpatient	Primary Care	Unknown	Total
Comprehensive	Body Functions	88.89	100.00	n/a	85.71	63.33	75.00	100.00	64.71
	Body Structures	33.33	28.57	0.00	n/a	28.57	100.00	100.00	20.00
	Activities and Participation	100.00	n/a	n/a	100.00	91.67	92.86	n/a	90.48
	Environmental Factors	100.00	100.00	100.00	100.00	90.91	83.33	100.00	86.67
	Total	85.71	58.33	66.67	90.91	70.00	82.98	100.00	**70.00**
Brief	Body Functions	44.44	100.00	n/a	57.14	26.67	30.00	100.00	23.53
	Body Structures	0.00	14.29	0.00	n/a	14.29	0.00	0.00	10.00
	Activities and Participation	40.00	n/a	n/a	0.00	16.67	14.29	n/a	19.05
	Environmental Factors	50.00	33.33	50.00	66.67	27.27	25.00	50.00	26.67
	Total	38.10	33.33	33.33	54.55	23.33	23.40	50.00	**21.25**
Rehab	Body Functions	33.33	50.00	n/a	42.86	16.67	20.00	100.00	14.71
	Body Structures	0.00	0.00	0.00	n/a	0.00	0.00	0.00	0.00
	Activities and Participation	60.00	n/a	n/a	100.00	58.33	35.71	n/a	38.10
	Environmental Factors	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
	Total	28.57	8.33	0.00	36.36	20.00	19.15	25.00	**16.25**

Appendix 5.1. Full list of MTNs, MTCs, MTUs and Trusts

MTN	MTC	MTU	Trust
East of England Trauma Network	Addenbrooke's Hospital Cambridge	Addenbrooke's Hospital Cambridge	Cambridge University Hospitals NHS Foundation Trust
Northern Trauma Network	James Cook University Hospital Middlesborough	James Cook University Hospital Middlesborough	South Tees Hospitals NHS Foundation Trust
South of England Major Trauma System	John Radcliffe Hospital Oxford	John Radcliffe Hospital Oxford	Oxford University Hospitals NHS Foundation Trust
London Major Trauma System	St Mary's Hospital London	St Mary's Hospital London	Imperial College Healthcare NHS Trust
London Major Trauma System	St George's Hospital London	St George's Hospital London	St George's University Hospitals NHS Foundation Trust
London Major Trauma System	Royal London Hospital	Royal London Hospital	Barts Health NHS Trust
London Major Trauma System	King's College Hospital London	King's College Hospital London	King's College Hospital NHS Foundation Trust
West Yorkshire Major Trauma Network	Leeds General Infirmary	Leeds General Infirmary	The Leeds Teaching Hospitals NHS Trust
East Midlands Trauma Network	Queen's Medical Centre Nottingham	Queen's Medical Centre Nottingham	Nottingham University Hospitals NHS Trust
Northern Trauma Network	Royal Victoria Infirmary Newcastle	Royal Victoria Infirmary Newcastle	The Newcastle upon Tyne Hospitals NHS Foundation Trust
South of England Major Trauma System	Southampton General Hospital	Southampton General Hospital	University Hospital Southampton NHS Foundation Trust
South of England Major Trauma System	Southmead Hospital Bristol	Southmead Hospital Bristol	North Bristol NHS Trust
Cheshire and Mersey Major Trauma Centre Collaborative	Aintree University Hospital Liverpool	Aintree University Hospital Liverpool	Aintree University Hospital NHS Foundation Trust
Peninsula Trauma Network	Derriford Hospital Plymouth	Derriford Hospital Plymouth	University Hospitals Plymouth NHS Trust
North Yorkshire and Humberside Major Trauma Network	Hull Royal Infirmary	Hull Royal Infirmary	Hull University Teaching Hospitals NHS Trust
South Yorkshire Major Trauma Network	Northern General Hospital Sheffield	Northern General Hospital Sheffield	Sheffield Teaching Hospitals NHS Foundation Trust
West Midlands Major Trauma Network	Queen Elizabeth Hospital Birmingham	Queen Elizabeth Hospital Birmingham	University Hospitals Birmingham NHS Foundation Trust

Lancashire Major Trauma Network	Royal Preston Hospital Lancashire	Royal Preston Hospital Lancashire	Lancashire Teaching Hospitals NHS Foundation Trust
South of England Major Trauma System	Royal Sussex County Hospital Brighton	Royal Sussex County Hospital Brighton	Brighton and Sussex University Hospitals NHS Trust
West Midlands Major Trauma Network	University Hospital Coventry	University Hospital Coventry	University Hospitals Coventry and Warwickshire NHS Trust
West Midlands Major Trauma Network	University Hospital of North Staffordshire Stoke on Trent	University Hospital of North Staffordshire Stoke on Trent	University Hospitals of North Midlands NHS Trust
Greater Manchester Major Trauma Service	Salford Royal Hospital	Salford Royal Hospital	Salford Royal NHS Foundation Trust
Greater Manchester Major Trauma Service	Manchester Royal Infirmary	Manchester Royal Infirmary	Manchester University NHS Foundation Trust
London Major Trauma System	Royal London Hospital	University College Hospital	University College London Hospitals NHS Foundation Trust
London Major Trauma System	Royal London Hospital	Royal Free Hospital	Royal Free London NHS Foundation Trust
London Major Trauma System	Royal London Hospital	Whittington Hospital	Whittington Health NHS Trust
London Major Trauma System	Royal London Hospital	Barnet Hospital	Royal Free London NHS Foundation Trust
London Major Trauma System	Royal London Hospital	North Middlesex Hospital	North Middlesex University Hospital NHS Trust
London Major Trauma System	Royal London Hospital	Whipps Cross Hospital	Barts Health NHS Trust
London Major Trauma System	Royal London Hospital	Homerton University Hospital	Homerton University Hospital NHS Foundation Trust
London Major Trauma System	Royal London Hospital	Newham University Hospital	Barts Health NHS Trust
London Major Trauma System	Royal London Hospital	Queens Hospital	Barking, Havering and Redbridge University Hospitals NHS Trust
London Major Trauma System	Royal London Hospital	Basildon Hospital	Basildon and Thurrock University Hospitals NHS Foundation Trust
London Major Trauma System	Royal London Hospital	Southend Hospital	Southend University Hospital
London Major Trauma System	St Mary's Hospital London	Chelsea and Westminster	Chelsea and Westminster Hospital NHS Foundation Trust
London Major Trauma System	St Mary's Hospital London	West Middlesex University Hospital	Chelsea and Westminster Hospital NHS Foundation Trust
London Major Trauma System	St Mary's Hospital London	Ealing Hospital	London North West University Healthcare NHS Trust
London Major Trauma System	St Mary's Hospital London	Hillingdon Hospital	The Hillingdon Hospitals NHS Foundation Trust

London Major Trauma System	St Mary's Hospital London	Watford General Hospital	West Hertfordshire Hospitals
London Major Trauma System	St Mary's Hospital London	Northwick Park Hospital	London North West University Healthcare NHS Trust
London Major Trauma System	St George's Hospital London	Kingston Hospital	Kingston Hospital NHS Foundation Trust
London Major Trauma System	St George's Hospital London	St Helier Hospital	Epsom and St Helier University Hospitals NHS Trust
London Major Trauma System	St George's Hospital London	Croydon University Hospital	Croydon Health Services NHS Trust
London Major Trauma System	St George's Hospital London	East Surrey Hospital	Surrey and Sussex Healthcare NHS Trust
London Major Trauma System	St George's Hospital London	Royal Surrey County Hospital	Royal Surrey County Hospital NHS Foundation Trust
London Major Trauma System	St George's Hospital London	Frimley Park Hospital	Frimley Health NHS Foundation Trust
London Major Trauma System	St George's Hospital London	St Peter's Hospital Chertsey	Ashford and St Peter's Hospitals NHS Foundation Trust
London Major Trauma System	King's College Hospital London	St Thomas' Hospital	Guy's and St Thomas' NHS Foundation Trust
London Major Trauma System	King's College Hospital London	University Hospital Lewisham	Lewisham and Greenwich NHS Trust
London Major Trauma System	King's College Hospital London	Queen Elizabeth Hospital London	Lewisham and Greenwich NHS Trust
London Major Trauma System	King's College Hospital London	Princess Royal University Hospital Orpington	King's College Hospital NHS Foundation Trust
London Major Trauma System	King's College Hospital London	Tunbridge Wells Hospital	Maidstone and Tunbridge Wells NHS Trust
London Major Trauma System	King's College Hospital London	Maidstone Hospital	Maidstone and Tunbridge Wells NHS Trust
London Major Trauma System	King's College Hospital London	Darent Valley Hospital	Dartford and Gravesham NHS Trust
London Major Trauma System	King's College Hospital London	Medway Maritime Hospital	Medway NHS Foundation Trust
London Major Trauma System	King's College Hospital London	William Harvey Hospital	East Kent Hospitals University NHS Foundation Trust
London Major Trauma System	King's College Hospital London	Kent and Canterbury Hospital	East Kent Hospitals University NHS Foundation Trust
London Major Trauma System	King's College Hospital London	Queen Elizabeth Queen Mother Hospital	East Kent Hospitals University NHS Foundation Trust
West Midlands Major Trauma Network	Queen Elizabeth Hospital Birmingham	Hereford County Hospital	Wye Valley NHS Trust
West Midlands Major Trauma Network	Queen Elizabeth Hospital Birmingham	Worcester Royal Hospital	Worcester Acute Hospitals NHS Trust
West Midlands Major Trauma Network	Queen Elizabeth Hospital Birmingham	Alexandra Hospital Redditch	Worcester Acute Hospitals NHS Trust

West Midlands Major Trauma Network	Queen Elizabeth Hospital Birmingham	Heartlands Hospital	University Hospitals Birmingham NHS Foundation Trust
West Midlands Major Trauma Network	Queen Elizabeth Hospital Birmingham	Walsall Manor Hospital	Walsall Healthcare NHS Trust
West Midlands Major Trauma Network	Queen Elizabeth Hospital Birmingham	New Cross Hospital	The Royal Wolverhampton NHS Trust
West Midlands Major Trauma Network	Queen Elizabeth Hospital Birmingham	Sandwell Hospital	Sandwell and West Birmingham Hospitals NHS Trust
West Midlands Major Trauma Network	Queen Elizabeth Hospital Birmingham	Russells Hall Hospital	The Dudley Group NHS Foundation Trust
West Midlands Major Trauma Network	Queen Elizabeth Hospital Birmingham	Birmingham City Hospital	Sandwell and West Birmingham Hospitals NHS Trust
West Midlands Major Trauma Network	University Hospital Coventry	Kettering General Hospital	Kettering General Hospital NHS Foundation Trust
West Midlands Major Trauma Network	University Hospital Coventry	Northampton General Hospital	Northampton General Hospital NHS Trust
West Midlands Major Trauma Network	University Hospital of North Staffordshire Stoke on Trent	Leighton Hospital	Mid Cheshire Hospitals NHS Foundation Trust
West Midlands Major Trauma Network	University Hospital of North Staffordshire Stoke on Trent	Wrexham Maelor Hospital	-
West Midlands Major Trauma Network	University Hospital of North Staffordshire Stoke on Trent	Royal Shrewsbury Hospital	The Shrewsbury and Telford Hospital NHS Trust
Northern Trauma Network	Royal Victoria Infirmary Newcastle	Northumbria Specialist Emergency Care Hospital	Northumbria Healthcare NHS Foundation Trust
Northern Trauma Network	Royal Victoria Infirmary Newcastle	South Tyneside District Hospital	South Tyneside and Sunderland
Northern Trauma Network	Royal Victoria Infirmary Newcastle	Sunderland Royal Hospital	South Tyneside and Sunderland
Northern Trauma Network	Royal Victoria Infirmary Newcastle	Queen Elizabeth Hospital (Gateshead)	Gateshead Health NHS Foundation Trust
Northern Trauma Network	Royal Victoria Infirmary Newcastle	University Hospital of North Durham	County Durham and Darlington NHS Foundation Trust
Northern Trauma Network	Royal Victoria Infirmary Newcastle	Scarborough Hospital	York Teaching Hospitals NHS Foundation Trust
Northern Trauma Network	Royal Victoria Infirmary Newcastle	Cumberland Infirmary	North Cumbria University Hospitals NHS Trust

Northern Trauma Network	James Cook University Hospital Middlesborough	University Hospital of North Tees	North Tees and Hartlepool NHS Foundation Trust
Northern Trauma Network	James Cook University Hospital Middlesborough	Darlington Memorial Hospital	County Durham and Darlington NHS Foundation Trust
East of England Trauma Network	Addenbrooke's Hospital Cambridge	Peterborough City Hospital	North West Anglia NHS Foundation Trust
East of England Trauma Network	Addenbrooke's Hospital Cambridge	The Queen Elizabeth Hospital (Norfolk)	The Queen Elizabeth Hospital King's Lynn
East of England Trauma Network	Addenbrooke's Hospital Cambridge	Norfolk and Norwich University Hospital	Norfolk and Norwich University Hospitals NHS Foundation Trust
East of England Trauma Network	Addenbrooke's Hospital Cambridge	James Paget University Hospitals	James Paget University Hospitals NHS Foundation Trust
East of England Trauma Network	Addenbrooke's Hospital Cambridge	West Suffolk Hospital	West Suffolk NHS Foundation Trust
East of England Trauma Network	Addenbrooke's Hospital Cambridge	The Ipswich Hospital	East Suffolk and North Essex NHS Foundation Trust
East of England Trauma Network	Addenbrooke's Hospital Cambridge	Colchester Hospital	East Suffolk and North Essex NHS Foundation Trust
East of England Trauma Network	Addenbrooke's Hospital Cambridge	Broomfield Hospital	Mid Essex Hospital Services NHS Trust
East of England Trauma Network	Addenbrooke's Hospital Cambridge	Princess Alexandra Hospital	The Princess Alexandra Hospital NHS Trust
East of England Trauma Network	Addenbrooke's Hospital Cambridge	Lister Hospital	East and North Hertfordshire NHS Trust
East of England Trauma Network	Addenbrooke's Hospital Cambridge	Luton and Dunstable Hospital	Luton and Dunstable University Hospital NHS Foundation Trust
East of England Trauma Network	Addenbrooke's Hospital Cambridge	Bedford Hospital	Bedford Hospital NHS Trust
Peninsula Trauma Network	Derriford Hospital Plymouth	Royal Cornwall Hospital	Royal Cornwall Hospitals NHS Trust
Peninsula Trauma Network	Derriford Hospital Plymouth	Torbay Hospital	Torbay and South Devon NHS Trust
Peninsula Trauma Network	Derriford Hospital Plymouth	Royal Devon and Exeter	Royal Devon and Exeter NHS Foundation Trust
Peninsula Trauma Network	Derriford Hospital Plymouth	North Devon District Hospital	Northern Devon Healthcare NHS Trust
South of England Major Trauma System	John Radcliffe Hospital Oxford	Milton Keynes General Hospital	Milton Keynes University Hospital NHS Foundation Trust

South of England Major Trauma System	John Radcliffe Hospital Oxford	Stoke Mandeville Hospital	Buckinghamshire Healthcare NHS Trust
South of England Major Trauma System	John Radcliffe Hospital Oxford	Wexham Park Hospital	Frimley Health NHS Foundation Trust
South of England Major Trauma System	John Radcliffe Hospital Oxford	Royal Berkshire Hospital	Royal Berkshire NHS Foundation Trust
South of England Major Trauma System	Southmead Hospital Bristol	Gloucestershire Royal Hospital	Gloucestershire Hospitals NHS Foundation Trust
South of England Major Trauma System	Southmead Hospital Bristol	Great Western Hospital	Great Western Hospitals NHS Foundation Trust
South of England Major Trauma System	Southmead Hospital Bristol	Royal United Hospital	Royal United Hospitals Bath NHS Foundation Trust
South of England Major Trauma System	Southmead Hospital Bristol	Yeovil District Hospital	Yeovil District Hospital NHS Foundation Trust
South of England Major Trauma System	Southmead Hospital Bristol	Musgrove Park Hospital	Taunton and Somerset NHS Foundation Trust
South of England Major Trauma System	Southmead Hospital Bristol	University Hospital Bristol	University Hospitals Bristol NHS Foundation Trust
South of England Major Trauma System	Southampton General Hospital	Basingstoke and North Hampshire Hospital	Hampshire Hospitals NHS Foundation Trust
South of England Major Trauma System	Southampton General Hospital	Queen Alexandra Hospital	Portsmouth Hospitals NHS Trust
South of England Major Trauma System	Southampton General Hospital	St Mary's Hospital	Isle of Wight NHS Trust
South of England Major Trauma System	Southampton General Hospital	Poole Hospital	Poole Hospital NHS Foundation Trust
South of England Major Trauma System	Southampton General Hospital	Dorset County Hospital	Dorset County Hospital NHS Foundation Trust
South of England Major Trauma System	Southampton General Hospital	Salisbury District Hospital	Salisbury NHS Foundation Trust
South of England Major Trauma System	Royal Sussex County Hospital Brighton	Conquest Hospital	East Sussex Healthcare NHS Trust
South of England Major Trauma System	Royal Sussex County Hospital Brighton	Eastbourne District General Hospital	East Sussex Healthcare NHS Trust
South of England Major Trauma System	Royal Sussex County Hospital Brighton	Worthing Hospital	Western Sussex Hospitals NHS Foundation Trust

South of England Major Trauma System	Royal Sussex County Hospital Brighton	St Richard's Hospital	Western Sussex Hospitals NHS Foundation Trust
West Yorkshire Major Trauma Network	Leeds General Infirmary	Airedale General Hospital	Airedale NHS Foundation Trust
West Yorkshire Major Trauma Network	Leeds General Infirmary	Bradford Royal Infirmary	Bradford Teaching Hospitals NHS Foundation Trust
West Yorkshire Major Trauma Network	Leeds General Infirmary	Harrogate District Hospital	Harrogate and District NHS Foundation Trust
West Yorkshire Major Trauma Network	Leeds General Infirmary	Huddersfield Royal Infirmary	Calderdale and Huddersfield NHS Foundation Trust
West Yorkshire Major Trauma Network	Leeds General Infirmary	Pinderfields Hospital	The Mid Yorkshire Hospitals NHS Trust
South Yorkshire Major Trauma Network	Northern General Hospital Sheffield	Barnsley Hospital	Barnsley Hospital NHS Foundation Trust
South Yorkshire Major Trauma Network	Northern General Hospital Sheffield	Doncaster and Bassetlaw Hospital	Doncaster ad Bassetlaw Teaching Hospitals NHS Foundation Trust
South Yorkshire Major Trauma Network	Northern General Hospital Sheffield	Chesterfield Royal Hospital	Chesterfield Royal Hospital NHS Foundation Trust
South Yorkshire Major Trauma Network	Northern General Hospital Sheffield	Rotherham Hospital	The Rotherham NHS Foundation Trust
South Yorkshire Major Trauma Network	Northern General Hospital Sheffield	North Lincolnshire Hospital	Northern Lincolnshire and Goole NHS Foundation Trust
South Yorkshire Major Trauma Network	Northern General Hospital Sheffield	Goole and District Hospital	Northern Lincolnshire and Goole NHS Foundation Trust
Lancashire Major Trauma Network	Royal Preston Hospital Lancashire	Royal Lancashire Infirmary	University Hospitals of Morecambe Bay
Lancashire Major Trauma Network	Royal Preston Hospital Lancashire	Furness General Hospital	University Hospitals of Morecambe Bay
Lancashire Major Trauma Network	Royal Preston Hospital Lancashire	Blackpool Victoria Hospital	Blackpool Teaching Hospitals NHS Foundation Trust
Lancashire Major Trauma Network	Royal Preston Hospital Lancashire	Royal Blackburn Hospital	East Lancashire Hospitals NHS Trust
North Yorkshire and Humberside Major Trauma Network	Hull Royal Infirmary	York Hospital	York Teaching Hospitals NHS Foundation Trust
North Yorkshire and Humberside Major Trauma Network	Hull Royal Infirmary	Scarborough General Hospital England	York Teaching Hospitals NHS Foundation Trust
North Yorkshire and Humberside Major Trauma Network	Hull Royal Infirmary	Diana Princess of Wales Hospital, Grimsby	Northern Lincolnshire and Goole NHS Foundation Trust

North Yorkshire and Humberside Major Trauma Network	Hull Royal Infirmary	Scunthorpe General Hospital England	Northern Lincolnshire and Goole NHS Foundation Trust
Cheshire and Mersey Major Trauma Centre Collaborative	Aintree University Hospital Liverpool	Royal Liverpool University Hospital	The Royal Liverpool and Broadgreen University Hospitals
Cheshire and Mersey Major Trauma Centre Collaborative	Aintree University Hospital Liverpool	Whiston Hospital	St Helens and Knowsley Teaching Hospitals NHS Trust
Cheshire and Mersey Major Trauma Centre Collaborative	Aintree University Hospital Liverpool	Warrington hospital	Warrington and Halton Hospitals NHS Foundation Trust
Cheshire and Mersey Major Trauma Centre Collaborative	Aintree University Hospital Liverpool	Arrowe Park Hospital	Wirral University Teaching Hospital NHS Foundation Trust
Cheshire and Mersey Major Trauma Centre Collaborative	Aintree University Hospital Liverpool	Countess of Chester Hospital	Countess of Chester Hospital NHS Foundation Trust
Cheshire and Mersey Major Trauma Centre Collaborative	Aintree University Hospital Liverpool	Southport and Formby District General Hospital	Southport and Ormskirk Hospital NHS Trust
Greater Manchester Major Trauma Service	Manchester Royal Infirmary	Royal Oldham Hospital	The Pennine Acute Hospitals NHS Trust
Greater Manchester Major Trauma Service	Manchester Royal Infirmary	Stepping Hill Hospital	Stockport NHS Foundation Trust
Greater Manchester Major Trauma Service	Manchester Royal Infirmary	Wythenshawe Hospital	Manchester University NHS Foundation Trust
Greater Manchester Major Trauma Service	Manchester Royal Infirmary	Royal Albert Edward Infirmary	Wrightington, Wigan and Leigh NHS Foundation Trust

Appendix 5.2. Full list of identified PILs

Title	Trust
Adult head injury	Cambridge University Hospitals NHS Foundation Trust
Choosing the right service to contact after a head injury	Cambridge University Hospitals NHS Foundation Trust
Head Injury	Cambridge University Hospitals NHS Foundation Trust
Head injury going home advice	Cambridge University Hospitals NHS Foundation Trust
Advice for people who have been concussed	Cambridge University Hospitals NHS Foundation Trust
Post-concussion syndrome	South Tees Hospitals NHS Foundation Trust
Head injury	South Tees Hospitals NHS Foundation Trust
Return to sport following concussion	South Tees Hospitals NHS Foundation Trust
Advice after a head injury	South Tees Hospitals NHS Foundation Trust
Advice after a head injury for adults with bleeding disorders	Oxford University Hospitals NHS Foundation Trust
Advice after your child's head injury	Oxford University Hospitals NHS Foundation Trust
Head injury advice	Imperial College Healthcare NHS Trust
Head injury in children	Barts Health NHS Trust
Head injury in children	King's College Hospital NHS Foundation Trust
Post-Traumatic Amnesia	Nottingham University Hospitals NHS Trust
Head injury	University Hospital Southampton NHS Foundation Trust
Head injury discharge advice	University Hospitals Plymouth NHS Trust
Child head injury discharge advice	University Hospitals Plymouth NHS Trust
Head injury in children	University Hospitals Plymouth NHS Trust
Going home after acquired brain injury	Hull University Teaching Hospitals NHS Trust
Head injury adults	Hull University Teaching Hospitals NHS Trust
Head injury discharge advice	Sheffield Teaching Hospitals NHS Foundation Trust
A patient guide to mild traumatic brain injury	University Hospitals Birmingham NHS Foundation Trust
Adult head injury	Brighton and Sussex University Hospitals NHS Trust

Fatigue after brain injury	Brighton and Sussex University Hospitals NHS Trust
Concussion	Brighton and Sussex University Hospitals NHS Trust
Head injury	Brighton and Sussex University Hospitals NHS Trust
Head injury advice - adult	Salford Royal NHS Foundation Trust
Concussion and return to sport	Salford Royal NHS Foundation Trust
Post-traumatic amnesia following a traumatic brain injury	Salford Royal NHS Foundation Trust
Head injury advice for carers of children	Salford Royal NHS Foundation Trust
head injury	Norfolk and Norwich University Hospitals NHS Foundation Trust
Head injury	James Paget University Hospitals NHS Foundation Trust
head injury advice for patients aged 16 years and over	Mid Essex Hospital Services NHS Trust
Head injury in adults	North Tees and Hartlepool NHS Foundation Trust
Head injury in children	North Tees and Hartlepool NHS Foundation Trust
Head injury advice: discharge advice for those aged 12 and over	Buckinghamshire Healthcare NHS Trust
Head injury (adults)	Royal Berkshire NHS Foundation Trust
Head injury children	Royal Berkshire NHS Foundation Trust
Head injury advice sheet	The Hillingdon Hospitals NHS Foundation Trust
Head injury adults	Royal Surrey County Hospital NHS Foundation Trust
Head Injury (Baby and Toddler)	Ashford and St Peter's Hospitals NHS Foundation Trust
Head Injury (Child)	Ashford and St Peter's Hospitals NHS Foundation Trust
Head injury in adolescents and young adults	University College London Hospitals NHS Foundation Trust
Head injury in children	University College London Hospitals NHS Foundation Trust
Head Injury a parent's guide	Whittington Health NHS Trust
Head injury (adult): aftercare advice	East Kent Hospitals University NHS Foundation Trust

Head injury (child): aftercare advice	East Kent Hospitals University NHS Foundation Trust
Acquired Brain Injury	North Cumbria University Hospitals NHS Trust
Information on driving after brain injury or illness	North Cumbria University Hospitals NHS Trust
Head injury in Adults and older children	North Cumbria University Hospitals NHS Trust
Head Injury - child	North Cumbria University Hospitals NHS Trust
Head Injury (Adult)	Dorset County Hospital NHS Foundation Trust
Head Injury (Child)	Dorset County Hospital NHS Foundation Trust
Managing fatigue after brain injury	Gloucestershire Hospitals NHS Foundation Trust
Brain Injury Team Early Discharge scheme	Gloucestershire Hospitals NHS Foundation Trust
Head injury: adult	Royal United Hospitals Bath NHS Foundation Trust
Head Injury - Child	Royal United Hospitals Bath NHS Foundation Trust
Head injury advice for adult patients	Yeovil District Hospital NHS Foundation Trust
Head injury advice for relatives and friends	Yeovil District Hospital NHS Foundation Trust
Advice for parent/carer of a child with a head injury	Yeovil District Hospital NHS Foundation Trust
Head injury advice	University Hospitals Bristol NHS Foundation Trust
Parent's guide to head injury	University Hospitals Bristol NHS Foundation Trust
Head injury in an adult	St Helens and Knowsley Teaching Hospitals NHS Trust
Head injury in a child	St Helens and Knowsley Teaching Hospitals NHS Trust
For parents or carers of young people who have sustained a head or brain injury	Torbay and South Devon NHS Trust
Mild Traumatic Brain Injury and Concussion	Torbay and South Devon NHS Trust
Discharge advice for carers of children who have a head injury	Northern Devon Healthcare NHS Trust
Discharge advice about head injury (people aged over 12 years)	Northern Devon Healthcare NHS Trust
Head injury (baby or toddler)	Northern Lincolnshire and Goole NHS Foundation Trust
Head Injury (child)	Northern Lincolnshire and Goole NHS Foundation Trust
Information for Patients, Relatives and Carers regarding Rehabilitation for Patients with Acquired Brain Injury	University Hospitals of Morecambe Bay
Recovering from a Head Injury	Blackpool Teaching Hospitals NHS Foundation Trust

Community Brain Injury Rehabilitation Service	Blackpool Teaching Hospitals NHS Foundation Trust
Looking after a Child with a Head Injury	Blackpool Teaching Hospitals NHS Foundation Trust
Head Injuries - child	Kettering General Hospital NHS Foundation Trust
Head injuries (adults)	Kettering General Hospital NHS Foundation Trust
Head injury in children	Stockport NHS Foundation Trust
Adult Head Injury	Stockport NHS Foundation Trust
Child Head injury	Stockport NHS Foundation Trust
Head Injury	Wrightington, Wigan and Leigh NHS Foundation Trust

Appendix 5.3. Original PILs quality checklist

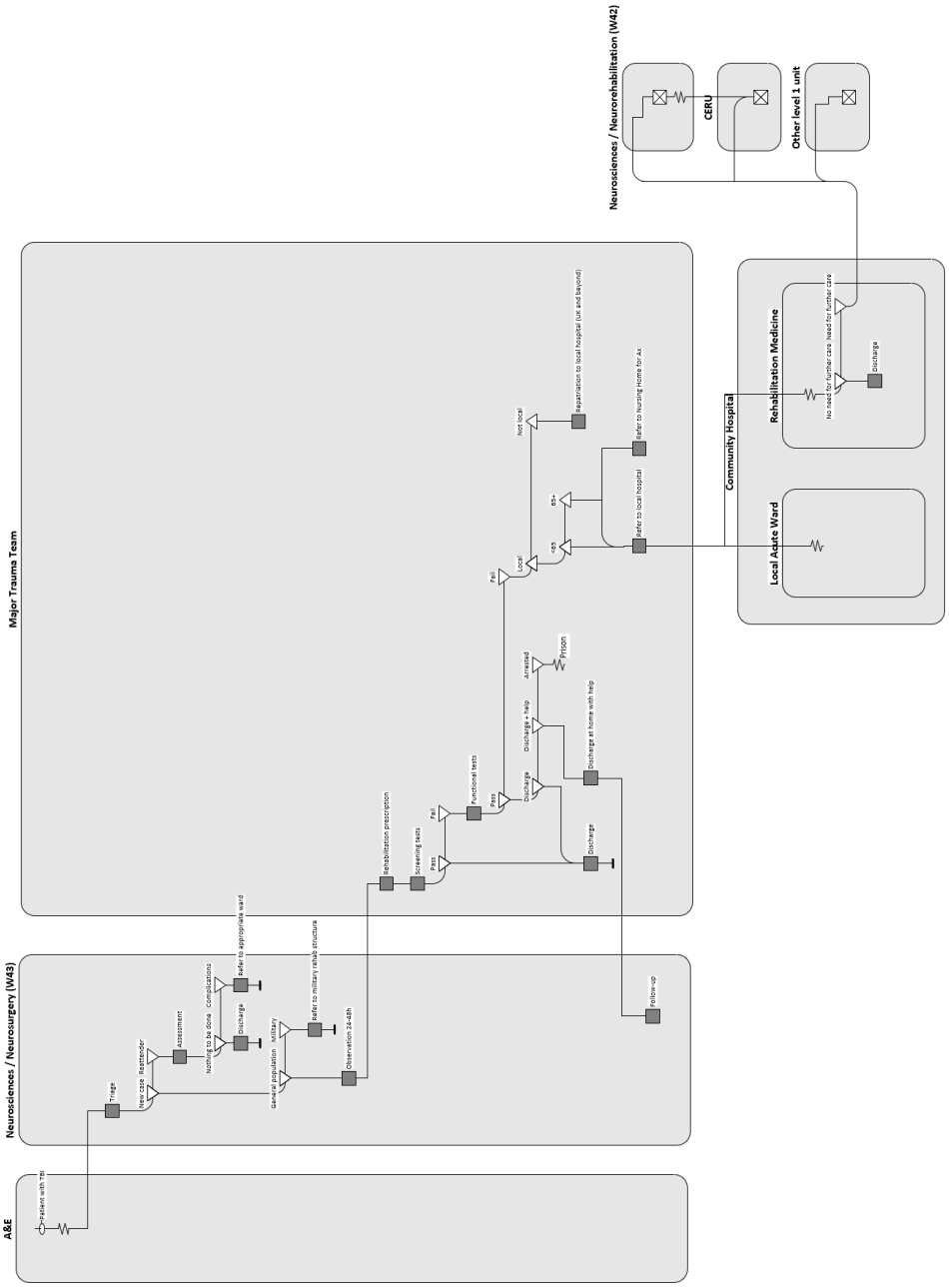
From Sustersic et al.[247]

Contents
Based on the latest evidence- based medicine
Declares the objectives of the PILs (writer's intention)
Explains causes, consequences, the usual course of the condition/disease
Explains the benefit/risks of a treatment, if any
Gives advice on what to do if a dose is missed: conduct to take
Advice on who, when and where to reconsult
Advice on "what to do": lifestyle recommendations, surveillance
Takes into account the patient's needs according to the literature
Written so that it personally addresses the reader, targeted, culturally appropriate
Contains easy- to- understand illustrations, diagrams or photographs
Names the person who wrote the leaflet and their position
States date of writing and/or last update
Gives references to sources of the information with dates
Avoids advertising or pharmaceutical brand names, uses generic names
Design
Favours patient interaction through questions
Short format
Layout of information structured, presented in a logical order (paragraphs and titles)
Not too compact, simple presentation, avoiding colour overload in drawings and boxes
Simple vocabulary (words or group of words)
Simple syntax (i.e. short sentences and active tense, active sentences)
Standard font (Arial, Times) avoiding small size (10 minimum)
Use of % to express frequencies, especially for risk perception
Contains a space to make notes
Other properties
Readability verified using a standard test
Critically read by at least two physicians in the discipline
Critically read by at least two potential users to test comprehension
Availability in electronic format to facilitate storage, update and traceability of use
Freely available online
Mechanisms for regular update of the information and installation of literature monitoring
Planned evaluation of PILs in quality RCT

Appendix 5.4. Detail of PILs checklist signposting categories

Charity
Headway
PAUL for brain recovery
UKABIF
Brain and Spine Foundation
Brain Injury Rehabilitation Trust (The Disabilities Trust)
Citizens advice
Brain and Spinal Injury Centre
Face-to-face healthcare service
Head Injury Nurse
Emergency Department
GP
Minor Injuries Clinic / Walk-in centres
Online/remote healthcare service
Patient Info
NHS website
111
PALS
Other government services
DVLA
Social services

Appendix 6.1. Preliminary meeting flow diagram example



Appendix 6.2. Expression of interest form

Research Participant Expression of Interest Form

Study ID	CP-TBI
Title of Project	Care Pathways in Traumatic Brain Injury
Name of Researchers	Ms Inès Kander, Prof Diane Playford, Dr Sudakshina Lahiri

Thank you for your interest in participation in our research about care pathways in Traumatic Brain Injury

Please read the Participant Information Sheet. If, after reading the information sheet, you are happy to participate and to be contacted by the researcher to schedule an interview, please complete the form below and return this page to Diane Playford. Alternatively, you can contact the researcher directly by emailing i.kander@warwick.ac.uk or calling 07447 154050.

Last name:_____

First name:_____

Telephone number:_____

Email address:_____

I prefer to be contacted by: ☐ Email ☐ Telephone

Signature: _____

Appendix 6.3. Participant Information Sheet

Brain Injury Research: Volunteers needed!

WARWICK

Version 2.4 – 01/03/2019

Traumatic Brain Injury: understanding access to healthcare

(Care Pathways in Traumatic Brain Injury)

My name is Inès Kander and I am a doctoral researcher at the University of Warwick.

I am interested in understanding what happens to people who have had a traumatic brain injury and are continuing to have symptoms in the months after their accident.

What is TBI

Traumatic Brain Injury is a type of of acquired brain injury caused by any mechanical force applied to the brain

Burden of TBI

Affects >1.4 million people in the UK each year

1/4 of people with mild TBI experience lasting problems

Cost of TBI > than stroke, personality disorders and epilepsy

Common causes of TBI

Road Traffic Collisions

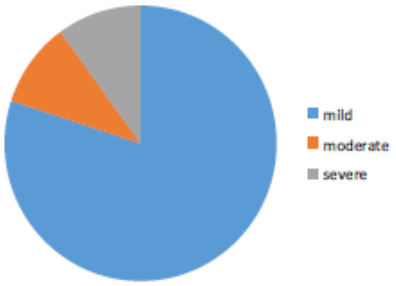
Sports injuries

Falls

Major issue in TBI care

Lack of guidelines for rehabilitation following TBI

Severity of TBI



Aims of Project

Evaluate current practice in TBI rehabilitation

Understand variations in patient care pathways

Identify the spectrum of health and social care services available to patients with TBI

Uncover the different patient pathways from acute to community care across health and social care services

Determine the decision-making points and the factors impacting the decision-making process

Why have I been asked to take part?

- You have come in contact with people with TBI as part of your professional role
- You are working within University Hospitals Coventry and Warwickshire NHS Trust, South Warwickshire NHS Foundation Trust, the NHS Coventry and Rugby CCG, or the NHS South Warwickshire CCG

What will I have to do?

You will be asked to participate in a face-to-face interview, that will last 1 to 2 hours to discuss the care pathways for people with TBI. You will be asked to focus on your role within that pathway, from communication with other stakeholders to factors that influence any decision-making process. You will not be asked to discuss any specific patient. The interview will be recorded on an audio digital recorder.

Do I have to take part?

No, the choice is entirely up to you. You will be asked to sign a consent form to confirm this. You can end the interview at any time without giving any reason. If you decide to withdraw from the study during the interview, the recording will be stopped and deleted. After the interview, and if you wish to do so, you will have up 48 hours to ask for your data (contact information, interview recording and transcript) to be removed from the research. by contacting the researcher at i.kander@warwick.ac.uk

Who has reviewed the study?

The study has been approved by the NHS Research Ethics Committee (**19/NI/0014**).

How will my data be used?

The University of Warwick is the sponsor for this study based in England. We will be using information from your interview in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Warwick will keep identifiable information about you 10 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at

https://warwick.ac.uk/services/idc/dataprotection/privacynotices/researchprivacynotice

or by contacting the Information and Data Compliance Team at GDPR@warwick.ac.uk

What will happen to my data?

As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This mean that when you agree to take part in a research study, such as this, we will use your data in the ways needed to conduct and analyse the research study.

We will be using information from your interview in order to undertake the study and will act as the data controller for this study. We are committed to protecting the rights of individuals in line with data protection legislation

The recording of the interview will be written up 48 hours after the interview by the interviewer so it can be analysed. At that stage, everything will be anonymized, so that your name, the name of any stakeholder will be removed. It will not be possible to withdraw your data from the research after this point. Once the recording has been written up and anonymized, it will be deleted. The transcripts will be stored in a password-protected file on a secure network. The transcript will be kept for 10 years, as per University of Warwick guidelines, after which they will be securely deleted.

WARWICK

Traumatic Brain Injury: understanding access to healthcare

I am interested, but...

What are the benefits for me?

Your participation is entirely voluntary and you will not be paid for taking part in this study. However, your participation may help uncover any issues with the current care provision for people with TBI, and help improve care for this patient population in the future.

What are the risks?

There are no risks associated with participation in this study.

What if I have a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed seriously. Please address any complaint to:

Deputy Director / Head of Research Governance
Research and Impact Services, University House
University of Warwick, Coventry, CV4 8UW
researchgovernance@warwick.ac.uk
02476 522746

You would like to take part?

If you would like to take part, have any questions or would like more information, please contact the researcher:

Ms Inès Kander
Doctoral Researcher
University of Warwick
i.kander@warwick.ac.uk
07447 154050

Appendix 6.4. Participate newsletter ad

Traumatic Brain Injury Study

Background

Traumatic Brain Injury is a widespread public health concern worldwide. Most TBIs are mild (i.e. concussion) and typically resolve on their own, but for 30% of people affected, symptoms last for weeks or months after their injury.

Research questions

What care services are available for people with persisting symptoms after TBI? What is the role of the GP in the care pathways?

What is the research project?

We would like to interview GPs to explore their views on caring for patients with persistent symptoms after TBI. Data will be collated with those from interviews with a range of healthcare professionals involved in the care of people with post-concussive syndrome to create a blueprint of care pathways for this patient group.

Interested?
Contact Inès Kander at
i.kander@warwick.ac.uk
or go to bit.ly/WarwickTBI
for more information.

Appendix 6.5. Consent Form

Date: 26/04/2019

Version: 1.4

WARWICK

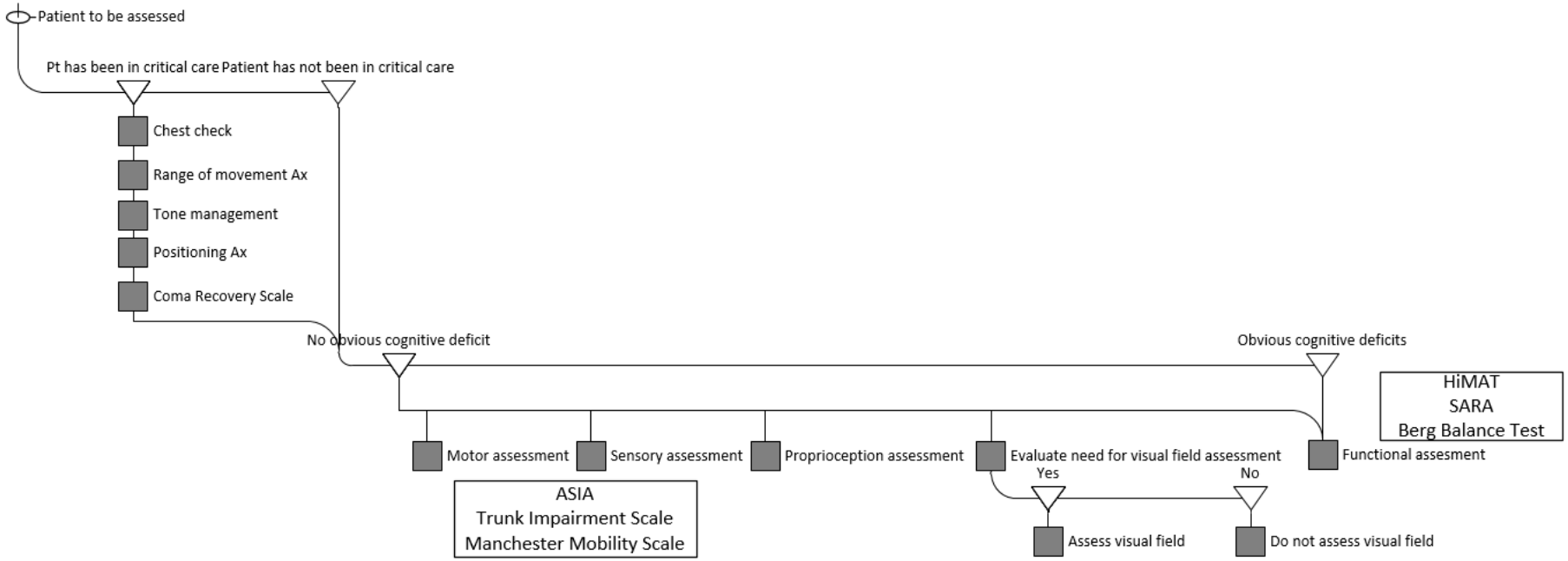
Research Participant Consent Form

Study ID	CP-TBI
Participant Identification Number	
Title of Project	Care Pathways in Traumatic Brain Injury
Name of Researchers	Ms Inès Kander, Prof Diane Playford, Dr Sudakshina Lahiri

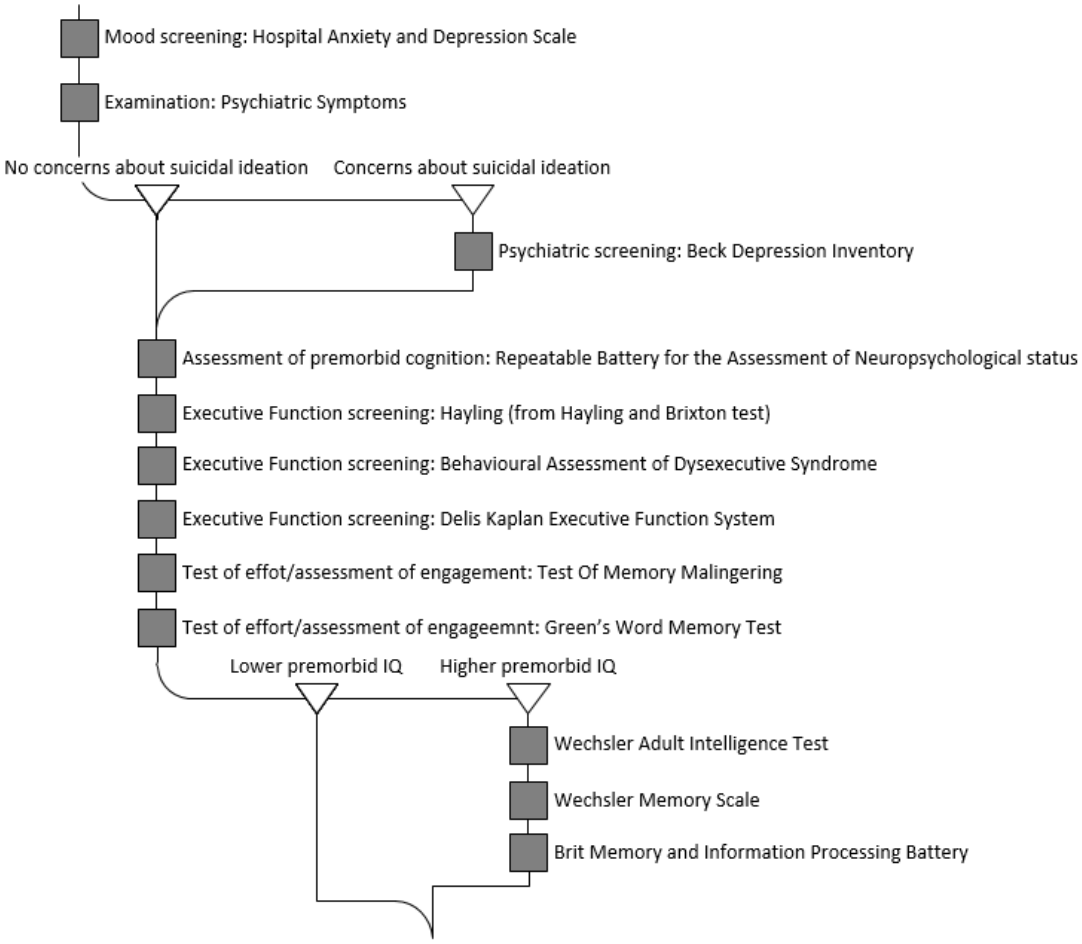
		Please initial all boxes
1	I confirm that I have read and understand the information sheet dated 01/03/2019 for the above study. I have had the opportunity to consider the information, as questions and have had these answered satisfactorily.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	
3	I understand that the interview will be recorded	
4	I understand that data collected during the study may be looked at by individuals at the University of Warwick where it is relevant to my taking part in this study; and NHS Trust pertaining to medical records for patients and research records for NHS staff.	
5	I understand that my data may be used in future research	
6	I agree to take part in the above study	

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Appendix 6.6. Detailed physiotherapy assessment (box 1)



Appendix 6.7. Detailed neuropsychology assessment (box 2)



Appendix 7.1. Participant information sheet

TRAUMATIC BRAIN INJURY APP

WARWICK

WARWICK
THE UNIVERSITY OF WARWICK

Inès Kander
BSc, MSc
Doctoral Researcher

Warwick Medical School
University of Warwick
Coventry CV4 8UW UK
www.warwick.ac.uk

E i.kander@warwick.ac.uk
T +44 (0)7447 154050

BACKGROUND

Traumatic Brain Injury (TBI) survivors have varied journeys to recovery, which makes it difficult to follow them up with traditional research methods. As a result, we do not have a clear understanding of what healthcare and support services survivors use and need after their injury.

To try and answer this question, Warwick Neurorehabilitation is working on the development of a phone app to be used in research. This app will track what services people are using and how often they are using them using the phone's location services. This is similar to how apps like Google Maps or Uber work, but this app will not track a person's every move: it will only be activated when the person is at a GP surgery, a pharmacy, a hospital, etc...

Knowing what healthcare and support services people are accessing in real time will also allow the app to send out very targeted and relevant research questions.

APP DEVELOPMENT TEAM

To make sure the app is relevant and acceptable for use, it is critical to receive input from TBI survivors from the early stages of the development process.

The co-development team will be formed of TBI survivors and researchers who will work on initial app development for 6 months starting in January 2019. The team will aim to meet once every 6 to 8 weeks and/or use an online platform (i.e. a private Facebook group, a WhatsApp chat, etc...)

This work is important for the bigger research project about TBI rehabilitation underway at Warwick Medical School, and will be written up for publication in scientific journals and a PhD thesis.

JOIN!

If you would like to join the co-development team, please fill out the form overleaf and return it to Janet Sewell at your next Headway meeting.

If you would like more information, you can get in touch with Inès Kander (i.kander@warwick.ac.uk).

Appendix 7.2. Expression of interest form

TRAUMATIC BRAIN INJURY APP

CONTACT INFORMATION

Last Name _____

First Name _____

Phone _____

Email _____

I prefer to be contacted by:

☐ Email ☐ Phone call ☐ Text/WhatsApp

COMMENTS/ SUGGESTIONS